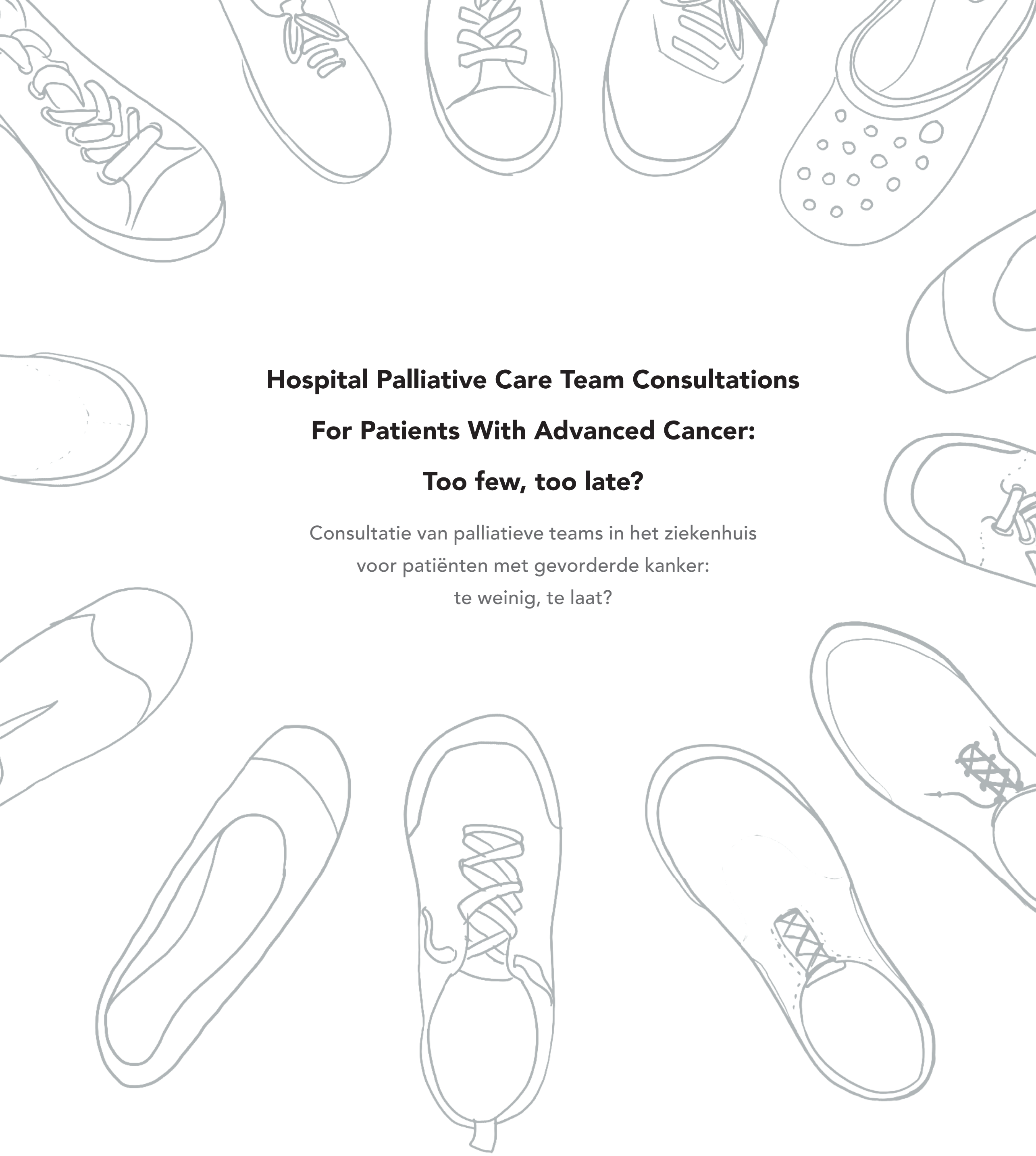
Hospital Palliative Care Team Consultations for Patients with Advanced Cancer:

Too few, too late?

Arianne Brinkman-Stoppelenburg



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Content of this thesis

Acknowledgements

The COMPASS study is one of the studies that is described in this thesis. This study was conducted in twelve hospitals in the Netherlands: Bravis Hospital, Elisabeth-TweeSteden Hospital, Erasmus Medical Center, Haga Hospital, Ikazia Hospital, Jeroen Bosch Hospital, Leiden University Medical Center, Maasstad Hospital, Northwest Clinics Alkmaar, Northwest Clinics Den Helder, OLVG Hospital and Rijnstate Hospital. We gratefully acknowledge the participation of patients and (bereaved) relatives. The study would not have been possible without their valuable contributions. Furthermore, we thank all nurses, physicians and members of the palliative care teams in these hospitals for their contributions to the study. A special thanks to Martin den Uijl for his assistance with the data collection.

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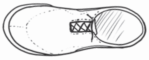


CHAPTER 1

General introduction

Palliative care

Palliative care developed in western societies in the second half of the twentieth century, as a response to the increasing marginalization of death in society and the medicalization of dying within the health care system.(1) Advances in public health and medical treatment caused a change in the pattern of causes of death, from infectious diseases or trauma to cardiac diseases and cancer. These shifts involved important changes in how we die. Instead of dying quickly, often within days, there is now often a period of illness of weeks or months preceding death.(2)

During the 1950's and 1960's physicians and socials scientists became interested in the clinical and social aspects of care for patients who were dying. A new view on dying emerged, including concepts of dignity, autonomy and meaning at the end of life. Systematic research on care of the dying increased.(1) Cicely Saunders, who was working as a nurse, social worker and physician, and who was the founder of St. Christopher's hospice in the United Kingdom, developed the concept of 'total pain' which includes the physical, social, emotional and spiritual aspects of suffering. Her pioneering work in caring for terminally ill patients became an inspiration for people throughout the world. In 1975, the term 'palliative care', that originates from the Latin word 'palliare' which means to cloak or cover, was introduced by the Canadian surgeon Balfour Mount, founder of palliative care in North America.(3, 4) Care for terminally ill patients evolved into palliative care, which applies the principles of holistic care earlier in patients' disease trajectories and in various settings, such as hospitals and the community.(1) Nowadays, palliative care is a medical specialization in a growing number of countries.(5) In 2002, the World Health Organization (WHO) formulated a definition stating that palliative care is an approach that improves the quality of life of all patients facing a life-threatening illness and their relatives (see box 1).

Box 1: WHO definition of palliative care.(6)

Palliative care, according to the WHO(6), 'is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, 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'.

Palliative care:
- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

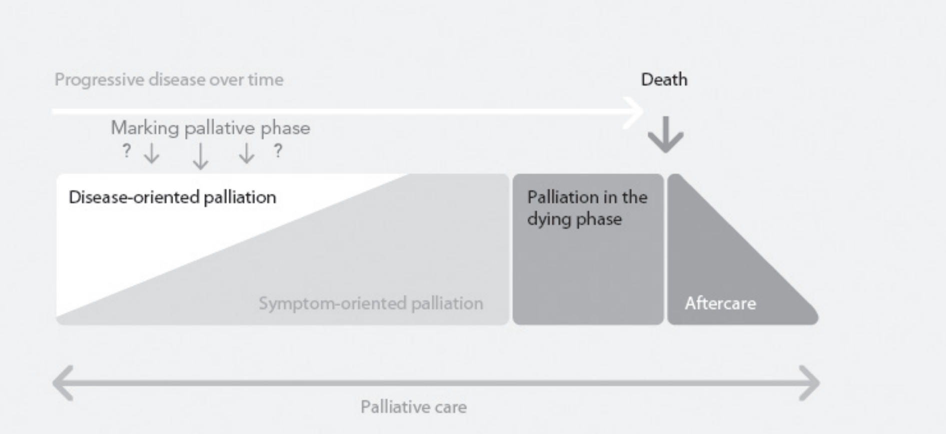
The definition of the WHO is a broad definition, which applies to all patients with a life-threatening illness. Many other definitions of palliative care exist, such as the definition of the National Consensus Project for Quality Palliative Care in the United States, which emphasizes aspects like autonomy, dignity, access to information and the provision and coordination of care by an interdisciplinary team.(7)

Through the years, the idea that palliative care is only relevant in the last weeks of life, was replaced by the concept that palliative care should be offered alongside curative treatment, to support people with chronic, progressive illness, sometimes over many years.(8) This is also expressed in the model of the palliative care trajectory, which was originally developed by Lynn and Adamson.(9) In this model, a distinction is made between four stages (Figure 1):(10)

1. Stage of more disease- than symptom-oriented palliation. During the stage of disease-oriented palliation care is aimed at maintaining and improving quality of life by treating the underlying disease. Prolongation of life can also be an aim in this stage. The health care professional checks to what extent patients and their relatives are aware of the temporary nature of the treatment effects on the underlying disease and what their hopes and expectations are with respect to prognosis and treatment. Furthermore, patient choices with respect to the treatment and the possible alternatives are regularly explored. Discontinuing or abandoning further disease-oriented treatment will also be discussed as a realistic possibility.

2. Stage of more symptom- than disease-oriented palliation. In this phase, care is aimed at maintaining and improving quality of life by focusing at the alleviation of symptoms. The principal care provider, patient and relative discuss the number, nature and severity of the symptoms and their significance for physical, psychological, social and spiritual functioning. Possible scenarios for the further development of these symptoms are discussed, including the patient's end-of-life wishes.
3. Dying phase. In this phase the dying person will be monitored for burdensome symptoms. Actions are mainly aimed at offering comfort and alleviation of suffering in the patient and at improving the quality of dying.
4. Aftercare phase. Palliative care also includes bereavement care. Caregivers who were involved in care in the palliative phase invite the relatives for a subsequent discussion should the need exist.

Figure 1: Stages of palliative care (10)



An important element of palliative care, especially during the disease-oriented phase, is advance care planning (ACP).(11) ACP enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and healthcare providers. ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that these can be taken into account should they, at some point, be unable to make their own decisions.(12) ACP is a means of extending the autonomy of patients to stages in life where they have become incompetent and can help people to make plans in line with their wishes and to have control over their last phase of life.(13) People can engage in ACP even before they are confronted with a life-threatening illness. However, in the first stages of the palliative care trajectory, specific attention should be paid to ACP.

Palliative Care in the Netherlands

The Dutch health care system is characterized by a strong emphasis on primary care. A relatively large proportion of all deaths occur at home in the Netherlands.(14) Patients who are in the last stage of life often receive care from their general practitioner and, if needed, home care nurses. In case a patient is in need of hospital and clinical specialist care, referral from a general practitioner is required, a process also referred to as 'gatekeeping'.(15)

The first specialized palliative care services in the Netherlands, involving two hospices and a palliative care unit in a nursing home, originate from the 1990s. In 1996, a national organization for palliative care, the Netherlands Palliative Care Network for Terminally Ill Patients (NPTN) was established. In that same year, the Minister of Health indicated the need to further develop palliative care. Six so-called "centers for the development of palliative care" (COPZ'en) were established which aimed to coordinate care, to develop educational modules and to increase expertise and carry out research activities.(16) Since that time, palliative care has developed rapidly, with support from the Dutch government. Government policy in the Netherlands supports the idea that palliative care is generalist care and should therefore be provided by all healthcare professionals whenever necessary.(18) If needed, specialist palliative care should be available, provided by caregivers with specific training and expertise in palliative care.(18) Dutch palliative care policy thus resembles the model of palliative care as described by Quill and Abernethy.(17) This model distinguishes primary palliative care, which includes skills all clinicians should have, and specialist palliative care, which includes skills for managing more complex and difficult problems. Core elements of palliative care, such as basic symptom management and aligning treatment with patients' goals, should be integrated in regular care. In case of complex problems, such as managing refractory symptoms or negotiating a difficult family meeting specialist palliative care should be available. However, in the Netherlands, palliative care is not a distinct medical specialty, as it is in many other countries.
In the Netherlands, specialist palliative care is mainly provided by a) a nationwide system of regional palliative care consultation teams, b) palliative care consultation teams in hospitals and c) in hospices and palliative care units in nursing homes and hospitals. The

regional teams are available since the start of this century. In 2015, 29 regional Palliative Care Teams (PCTs) with 303 consultants provided consultations to general practitioners (in 74% of all consultations), medical specialists (14%), nurses and carers (7%) and nursing home physicians (3%).(19)

In 2017, the Quality Framework for Palliative Care in the Netherlands was launched.(20) Healthcare professionals, together with patients and their relatives and health care insurers, developed this framework which describes what the quality of palliative care in the Netherlands should be. In this framework it is emphasized that "generalist-health care professionals and, when required, specialist healthcare professionals and volunteers, work together as an interdisciplinary team in close collaboration with patients and their families, and tailor treatment to the stated values, wishes and needs of the patient."(20) This statement underlines the importance of interdisciplinary teamwork as an essential component of palliative care.(21, 22)

Palliative care for cancer patients

Cancer has become one of the most common causes of death. In the Netherlands, each year approximately 45.000 people die from cancer, which is about one third of all deaths.(23) In the 1950's, both professional and public interest in cancer was focused on curative treatment and there was little interest in care of people dying from cancer.(24) This changed in the second half of the twentieth century.(1)

The development of palliative care is in fact rooted in oncology care "which has shaped the conceptual model of palliative care and provided a population of patients with the obvious potential to benefit from a new approach to the management of those with advanced disease."(24) Today, the largest group of patients who are referred to specialized palliative care services consists of patients with incurable cancer, in the Netherlands as well as in other countries.(17, 19) When cancer progresses, patients may suffer from multiple and severe symptoms and problems, which can seriously affect their quality of life.(25-27) Patients not only suffer from physical symptoms such as pain or fatigue, but also from psychological, social and spiritual problems.(28, 29) Several international organizations have recommended that palliative care principles and practice should be integrated early in the care of patients with advanced cancer, and that the start of the palliative phase should be clearly marked for each individual patient.(6, 30-32) Despite the emphasis on primary care and the large percentage of home deaths in the

Netherlands, about 50% of patients with cancer are hospitalized at least once in the last three months of life.(33) Of patients who died of cancer in 2008, 46% died at home, 26% in the hospital, 19% in nursing homes and 7% in palliative care institutions.(33)

Palliative Care in hospitals

Hospital care is usually focused on diagnosis, treatment and discharge. Several studies have reported unmet needs and deficiencies in the quality of care of patients dying in the hospital.(34, 35)

In hospitals, specialist palliative care is often provided by specialist palliative care teams (PCTs) that can be consulted by physicians or nurses working in the hospital. Consultation is the act of seeking assistance from (an)other physician(s) or health care professional(s) for diagnostic studies, therapeutic interventions, or other services that may benefit the patient.(36) In the literature, ethical principles and concepts for providing effective consultations are described.(36, 37) Both the referring physician and the consultant have a responsibility to maximize the effectiveness of the consultation in improving patient care. The level of consultation may range from a single visit, continuing collaborative care to the transfer of primary clinical responsibility.(36)

Upon their involvement, PCTs typically provide a detailed holistic assessment of the patients' and family´s situation. They assess patients' symptoms and their physical, emotional, social and spiritual problems, prioritize these and propose a care plan to address them. The extent to which PCTs provide care themselves or only advise the primary caregivers varies. Most PCTs consist of professionals from different specialties, such as medical oncologists, neurologists, anesthesiologists, nurses, psychologists, social workers and spiritual caregivers. The structure and activities of PCTs in hospitals vary. Some PCTs are strongly embedded in the hospital organization and supported by the management of the hospital, whereas others are not. Some teams are involved in education within or outside the hospital. The first hospital PCTs in the Netherlands originate from the late 1990's. An inventory of the Netherlands Comprehensive Cancer Organisation in 2013 showed that almost half of the hospitals (45 out of 92), were in different stages of implementing PCTs.(38) In order to improve hospital palliative care, the Dutch Federation of Oncological Societies (SONCOS) has stated in their "Multidisciplinary standards for oncological care in the Netherlands" that each hospital should have a PCT by 2017.(39) This development underlines the important role PCTs are expected to play in supporting professional caregivers and in providing specialized palliative care in the hospital.

The evidence that involvement of hospital PCTs has positive effects on quality of life in patients with advanced cancer is gradually increasing, and mainly comes from the United States.(40-42) PCT involvement has also been shown to be associated with a reduction in health care use resulting in significant cost savings.(13, 14, 16–18) It is however unclear to what extent these findings can be generalized to other countries with different health care systems and cultures, such as the Netherlands.

A special form of consultation in end-of-life care

Whereas consultation of palliative care expertise is always voluntary and left to the discretion of the attending physician, consultation is obligatory in case of euthanasia or physician-assistance in suicide. In Dutch society and health care there is a long tradition of relative openness towards issues around death and dying. Even before the development of palliative care, there has been a longstanding debate among medical practitioners, lawyers, ethicists, politicians and the general public on the administering of lethal drugs by a physician with the intention to end a patient's life on the patient's explicit request. (43, 44) This resulted in the Euthanasia Law in 2002, in which euthanasia and physician-assisted suicide are, under strict conditions, regulated. The legal requirements include the presence of a voluntary and well-considered request, unbearable suffering without prospect of improvement, absence of a reasonable alternative, the provision of adequate information to the patient and the application of a technically appropriate method to end life. Furthermore, an independent physician should be consulted to check whether the requirements of due care can be met. SCEN (Support and Consultation on Euthanasia in the Netherlands) physicians provide these consultations.(45)

Outline of this thesis

This thesis includes several studies on consultation in palliative and end-of-life care in the Netherlands. These studies are described in two parts.

Part 1: The COMPASS study

We performed an observational study to investigate the use, effe***c***ts and c***o***sts of consultation tea***m***s for ***pa***lliative care in ho***s***pital***s*** for patients with incurable cancer in the Netherlands, the COMPASS study. We performed this study in twelve hospitals throughout the Netherlands. Data were collected between February 2013 and March

2015, among patients, bereaved relatives, physicians and members of palliative care teams in hospitals. The design of the COMPASS study is described in chapter 2.

The main research questions for this study were:

- What are determinants and characteristics of palliative care team consultation in Dutch hospitals? This research question is addressed in chapter 3.
- What are the effects of PCT consultation on quality of life for patients with incurable cancer? This study is described in chapter 4.
- Is there an association between PCT consultation and health care consumption and costs for patients with incurable cancer? This research question is addressed in chapter 5.

Part 2: Consultation in palliative and end-of-life care

We performed several additional research studies on consultation in palliative and end-of-life care.

In a post-bereavement study of patients who deceased in our university hospital, we asked bereaved relatives on their perspectives of quality of dying and studied the impact of PCT consultation. This study is presented in chapter 6.

In a questionnaire study among all hospitals in the Netherlands we studied how many of them had a PCT service available in 2015. The results are described in chapter 7.

Further, we studied developments in end-of-life decision making practices (see chapter 8) and the extent to which supportive caregivers are consulted in care during the last phase of life (see chapter 9). We also studied a specific type consultation, namely consultation of SCEN physicians in case of euthanasia requests (see chapter 10).

Finally, whereas advance care planning is one of the major contributions of palliative care, we performed a literature review on evidence of the effects of advance care planning. This literature review is described in chapter 11.

The thesis concludes with a general discussion on the findings and the methods and with some implications for the future research, policy and clinical practice.

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CHAPTER 2

Palliative care consultation services in hospitals in the Netherlands: the design of the COMPASS study.

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BMC Palliative Care. 2015 Dec 1:14:68

Abstract

Background

Patients with an advanced incurable disease are often hospitalized for some time during the last phase of life. Care in hospitals is generally focussed at curing disease and prolonging life and may therefore not in all cases adequately address the needs of such patients. We present the COMPASS study, a study on the effe***c***ts and c***o***sts of consultation tea***m***s for ***pa***lliative care in ho***s***pital***s***.

This observational study aims to investigate the use, effects and costs of PCT consultation services for hospitalized patients with incurable cancer in the Netherlands.

Methods / design

The study consists of 3 parts:

1. A questionnaire, interviews and a focus group discussion to investigate the characteristics of PCT consultation in 12 hospitals. PCTs will register their activities to calculate the costs of PCT consultation.
2. Cancer patients for whom the attending physician would not be surprised that they would die within 12 months will be included in a medical file search in three hospitals. Medical records will be investigated to compare care, treatment and hospital costs between patients with and patients without PCT consultation.
3. In the other nine hospitals, we will perform a longitudinal study, and compare quality of life between 100 patients for whom a PCT was consulted with 200 patients without PCT consultation at six time points. Propensity score matching will be used to adjust for differences between both patient groups. Patients will be followed for three months after inclusion. Quality of life will be assessed with the Palliative Outcome Scale, the EuroQol-5D and the EORTC-QLQ-C15 PAL. Satisfaction with care in the hospital is measured with the IN-PATSAT32. The cost impact of PCT consultation will also be explored.

Discussion

This is the first multicenter study on PCT consultation in the Netherlands. The study will give valuable insight in the process, effects and costs of PCT consultation in hospitals. It is anticipated that PCT consultation has a positive effect on patients' quality of life and satisfaction with care and will lead to less hospital care costs.

Background

Patients with an advanced incurable disease often spend some time in hospital during the last months of life.(1) When death is approaching for such patients, the goals of care need to be realigned. However, burdensome medical interventions are often prolonged until the end of life, without any beneficial effect.(2-5) As a result, end-of-life care in hospitals tends to involve high costs while failing to address patients' needs and to provide them with a dignified death.

Palliative care is aimed at acknowledging patients' impending death and at reconsidering goals of care.(6) It is an approach that improves the quality of life and their families facing the problems associated with life-threatening illness, 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.(7) Palliative care is not only provided at the end of life, but also in earlier stages, sometimes alongside disease-directed interventions that are aimed at curing disease or prolonging life.(8) Basic palliative care, such as basic symptom management and supporting patients to align their treatment choices with their values and goals, should be delivered by any health professional attending patients in the last phase of life. Other, more complex forms of care, such as managing refractory symptoms or negotiating a difficult family meeting, may require involvement of specialized palliative care professionals.(8)

The effects of Palliative Care Team Consultation

Several studies have shown that the deployment of specialized palliative care teams (PCTs) in hospitals is associated with better outcomes for patients with advanced disease.(9) Their involvement was found to improve patients' quality of life (10-12), their satisfaction with care (12, 13) and communication about goals of care, resulting in less diagnostic testing and less use of inappropriate technology and intensive care.(14) In a recent study Temel et al. found that patients with lung cancer receiving early palliative care had a better quality of life, received less aggressive treatment and had a longer survival compared to patients receiving usual care without palliative care involvement.(15) Consultation of palliative care services for patients with advanced incurable disease may also influence health care costs, through its focus on assessing patients' goals of care and providing treatments that are concordant with these goals. Several studies have demonstrated significant cost savings as a result of palliative care involvement.(13, 14, 16-18) The largest group of patients who are referred to specialized palliative or end-of-life care services consists of patients with incurable cancer, in the Netherlands as well as in other countries.(19, 20) However, the provision of palliative care to patients with advanced cancer often remains suboptimal. Informational, emotional and physical needs are frequently unmet among patients with incurable disease.(21-24) Studies show that PCT consultation is only used for a minority of all patients with advanced disease, which suggests that this service is used sub-optimally.(25) This might be due to a lack of awareness of the availability and potential contribution of this service among regular health care professionals. Furthermore, it is known that PCTs are often consulted late in the disease trajectory.(26) There may also be barriers to consultation, such as the lack of referral criteria, and the view that the involvement of palliative care is a signal that the primary health care professionals have given up all hope for a patient.(27-29)

Palliative care team consultation in hospitals in the Netherlands

The Netherlands has a nationwide system of palliative care consultation services, that is predominantly used by general practitioners for patients staying at home.(30-32) More recently, hospitals have started establishing PCT consultation services. An inventory of the Netherlands Comprehensive Cancer Organisation in 2013 showed that at least 45 hospitals in the Netherlands, out of a total of 92, were in different stages of implementing such consultation services.(33) Most hospital-based specialist PCTs can be consulted by physicians or nurses working in the hospital. Upon their involvement, PCTs typically provide a detailed holistic assessment of the patients' and family´s situation. They assess patients' symptoms and their physical, emotional, social and spiritual problems, prioritize these and propose a care plan to address them. The extent to which PCTs provide care themselves or only advise the primary caregivers varies. Most PCTs consist of professionals from different specialties, such as oncologists, neurologists, anesthesiologists, nurses, and psychosocial and spiritual caregivers. The structure and activities of PCTs in hospitals vary. Some PCTs are strongly embedded in the hospital and supported by their hospital boards, whereas others are not. Some teams are involved in education within or outside the hospital.

Objectives

Evidence on the effects of PCT consultation in hospitals on patient outcomes and health care costs mainly comes from studies from the United States. It is unclear to what extent these results can be generalized to other countries with different health care systems and cultures, such as the Netherlands. We will therefore perform an observational study to investigate the use, effects and costs of PCT consultation services for hospitalized patients with incurable cancer in the Netherlands. We will

1. assess the characteristics of PCT consultation services in different hospitals,
2. study whether PCT consultation for patients with incurable cancer has an effect on in-hospital medical care,
3. explore whether PCT consultation for patients with incurable cancer has beneficial effects on patients' quality of life and satisfaction with care and
4. explore whether PCT consultation reduces costs of care and might be a cost-effective intervention.

Methods

We will collect data in three substudies.

Characteristics of PCT consultation in Dutch hospitals
We will use a structured questionnaire to study structure and process characteristics of PCT consultation services in 12 hospitals in the Netherlands. All teams will be asked to fill out this questionnaire, which contains multiple choice and open questions regarding the disciplines that are represented in the PCT, the process of consultation and the way the teams monitor and improve the quality of their consultation. Further, all teams will be invited to participate in group discussions or individual interviews to explore differences between teams and PCT members' experiences of barriers and facilitators of a successful consultation service.

The effect of PCT consultation for patients with incurable cancer on medical care
In three hospitals, care and treatment as provided to patients with advanced incurable cancer for whom a PCT is consulted during their stay in the hospital will be compared with care and treatment as provided to comparable patients without PCT consultation. Inclusion criteria are that patients are 18 years or over and that the attending physician answers "no" to the question "Would you be surprised if this patient would die in the next year?".(34) We will check the medical files of all eligible patients to assess the use of diagnostic procedures, medication, chemotherapy and other medical interventions, and days spent in hospital, during 3 months after inclusion. The attending physician will be asked to provide information on the patient's diagnosis, performance status, co morbidity and life expectancy, by filling out a short questionnaire. For those patients for whom a PCT is consulted, PCTs will be asked to fill out a questionnaire about the content of the consultation.

The use of medical care and the number of days spent in hospital will be compared between patients with PCT consultation and patients without PCT consultation, while taking into account differences in patients' medical characteristics.

The effect of PCT consultation for patients with incurable cancer on quality of life and the cost effectiveness of PCT consultation

In 9 hospitals we will study the effect of PCT consultation for in-hospital patients with incurable cancer on quality of life. In order to get a good overview of different types of hospitals, a university hospital, teaching and general hospitals will be included. In order to include sufficient comparable patients receiving usual care 3 hospitals without a PCT will be included.

Inclusion criteria are that patients are 18 years or over; that the attending physician answers "no" to the question "Would you be surprised if this patient would die in the next year?"(34); and that the patient is expected to stay in the hospital for at least 3 days. The latter criterium is added to enable an informed consent procedure. Patients will be included upon arrival in the hospital. Eligible patients will receive an information letter and will be informed and asked to participate by an attending nurse. Patients who agree to participate will be followed during three months, regardless of where they stay. The attending physician will be asked to fill in a questionnaire to assess medical information such as diagnosis, performance status, co morbidity and life expectancy. Palliative care consultation teams are asked to fill a questionnaire about the content of the consultation. Patients will be asked to fill out a number of subsequent questionnaires. In these questionnaires, quality of life is assessed with the EORTC QLQ-C15 PAL.(35) We will also measure quality of life with the Palliative Outcome Scale (36) and the EuroQol-5D (37), because of the lack of consensus on the most appropriate quality of life instrument for patients with incurable disease.(38) Secondary measures are symptom scores for pain, dyspnea and anxiety (EORTC QLQ-C15); patient satisfaction with care, using the INPATSAT 32 questionnaire.(39, 40) Quality of life will be assessed longitudinally at six moments in time: at day 4, 7, 14, 30, 60 and 90 after admission to the hospital; satisfaction with care will be assessed at day 14 after admission.

We aim to include 100 patients for whom a PCT was consulted and compare them with at least 200 patients receiving usual care. With such a sample size we will be able to detect a difference in quality of life as measured by the EORTC QLQ-C15 PAL at day 14 of 0.4 in standard deviation units (Cohen's D = effect size) with alpha of 0.05 (2-sided) and power of 90%.

Data analysis

Due to the observational design of the study it is likely that there is an imbalance of prognostic factors between patients who are and patients who are not receiving PCT consultation. As a consequence, the estimated effects of PCT consultation can be biased. We will adjust for imbalance in the statistical analysis by using propensity scores.(41-43) We will develop a propensity score model to assess the probability that a patient would have been offered PCT consultation. Patient characteristics to be included in this model are age, sex, marital status, primary diagnosis, reason for hospitalization (e.g. treatment of complex symptoms, palliative chemotherapy, treatment of complications), life expectancy, functional status, attending physician specialty, comorbidity, and hospital of admission.(14, 16) The logit of the propensity score will be used to match each patient receiving PCT consultation with one or more usual care patients.

Quality of life scores at different time points will be compared between the PCT and care as usual groups with repeated measurement analysis. A model will be fitted that includes matched-pairs, time, treatment group, the baseline score, and interaction between time and treatment group.

Economic evaluation

The economic evaluation of PCT consultation in hospitals will concern a period of three months after admittance of patients to the hospital.

Data from substudy 2 will be used to perform a cost-minimization analysis including hospital costs. We will distinguish intramural medical costs (inpatient days, professional health caregivers' activities, medical procedures). Real medical costs will be calculated by multiplying the volumes of health care use with the corresponding unit prices. Costs for inpatient days in hospitals will be estimated as real, basic costs per day using detailed hospital administrative information. We will make a distinction between the costs in general hospitals and university hospitals. The unit price of the PCTs will be determined with the micro-costing method,(44) which is based on a detailed assessment of all resources used.

Data from substudy 3 will be used to perform an economic evaluation from a health care perspective. We will calculate total medical costs per patient, including intramural and extramural medical costs (home care, nursing home days, general practitioner activities). For the calculation of the intramural medical care costs and the unit price of PCTs we use the same methodology as for the cost-minimization study. For the calculation of extramural medical costs, we will use charges as published in Dutch guidelines as a proxy of real costs.(45) The cost-effectiveness of PCT consultation will be assessed by calculating the incremental cost-effectiveness ratio (ICER), defined as the difference in costs of PCT consultation compared to usual care, divided by the average change in patients' quality of life. The primary effect measure for the economic evaluation of PCT consultation is quality of life as measured by the EORTC QLQ-C15 PAL. Because of the short time horizon, costs and effects will not be discounted.

Feasibility of recruitment

We expect to be able to include the needed number of patients in a period of 18 months. The participating departments will be asked to assign a nurse who is responsible for checking the eligibility of all admitted patients. This method proved to be successful in a previous study.(3) Patients with incurable cancer have been found to be at least as willing to participate in scientific research as patients in other stages of disease.(3, 46) Whereas our study is an observational study in which patients are only asked to fill out a number of questionnaires, our modest assumption of a 60% participation rate seems justified.

Ethical considerations

The research protocol was submitted to the Medical Ethical Research Committee of the Erasmus Medical Center who declared that there were no objections to the performance of this study.

Substudy 1 is not related to patients but to caregivers. Caregivers consented to participate in the group discussions or individual interviews. For substudy 2, according to national regulations, informed consent does not have to be obtained, because data on medical care and decision making will be gathered and stored locally and anonymously in a database. For substudy 3, written informed consent will be obtained from all participants.

Discussion

The objective of the COMPASS study is to assess the process and outcomes of hospital palliative care consultation in the Netherlands. The study has several potential strengths, weaknesses, threats and opportunities that are associated with the design of the study and with the specific population.

Strengths and weaknesses

To our knowledge this is the first study to assess the effects of hospital palliative care consultation in the Netherlands. The number of participating hospitals (12) and PCTs

(9), representing academic, teaching and general hospitals, is a strength of this study because in this way we gain insight in different settings. Furthermore, we will study PCT consultation in 'real life' and not in an experimental setting. However, the observational design of the COMPASS study can also be viewed as a weakness. Randomized studies on the effects of health service changes in palliative and end-of-life care are often not possible, due to ethical and practical constraints. Firstly, specialized palliative care services may not only have an impact on individual patient care, but also on general attitudes of hospital caregivers towards care for patients in the last stage of life, which would contaminate assessments in the control groups. Secondly, several hospitals, especially those that are at the forefront of developing palliative care have already implemented PCT consultation facilities for several years, which makes randomized evaluation of such facilities impossible. When randomized trials are not feasible, as is the case in our study, a well-designed observational study is an appropriate alternative.(47) Some previous studies on the effects and costs of specialized palliative care services were observational and used novel statistical techniques, such as propensity scores, to define comparable patient groups.(22)

Threats and opportunities

The threats to the successful conduct of this study relate mainly to the inclusion of patients. Nurses may be reluctant to ask patients for informed consent as participation in research may impose undue burden on patients and caregivers.(48) However, studies have found that many patients with advanced illnesses actually appreciate to participate in research.(48) Furthermore, it is known that PCTs are often consulted relatively late in the disease trajectory (27, 49), which means patients may not be able to participate by filling in questionnaires. Furthermore, some patients will be lost to follow up, which is inherent to the study population.

Implications

This study will provide insight in the process and outcomes of PCT consultation in Dutch hospitals. This knowledge is important for existing and new PCTs. The outcomes can be used to optimize hospital-based PCT consultation services for patients with advanced illnesses.

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CHAPTER 3

The COMPASS study: an observational study on the characteristics of palliative care team consultation in hospitals

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CHAPTER 4

The impact of palliative care consultation on quality of life of patients with advanced cancer in Dutch hospitals: an observational study

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CHAPTER 5

The association between palliative care team consultation and hospital care for patients with advanced cancer: an observational study in 12 Dutch hospitals

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CHAPTER 6

Palliative care team consultation and quality of death and dying in a university hospital: a secondary analysis of a prospective study.

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Abstract

Purpose

Involvement of palliative care experts improves the quality of life and satisfaction with care of patients who are in the last stage of life. However, little is known about the relation between palliative care expert involvement and quality of dying (QOD) in the hospital. We studied the association between palliative care team (PCT) consultation and QOD in the hospital as experienced by relatives.

Methods

We conducted a secondary analysis of data from a prospective study among relatives of patients who died from cancer in a university hospital and compared characteristics and QOD of patients for whom the PCT was or was not consulted.

Results

175 out of 343 (51%) relatives responded to the questionnaire. In multivariable linear regression PCT was associated with a 1.0 point better QOD (95% CI 0.07-1.96). In most of the subdomains of QOD, we found a non-significant trend towards a more favorable outcome for patients for whom the PCT was consulted. Patients for whom the PCT was consulted had more often discussed their preferences for medical treatment, had more often been aware of their imminent death and had more often been at peace with their imminent death. Further, patients for whom the PCT was consulted and their relatives had more often been able to say goodbye. Relatives had also more often been present at the moment of death when a PCT had been consulted.

Conclusion

For patients dying in the hospital, palliative care consultation is associated with a favorable QOD.

Introduction

Patients with an advanced incurable disease are often admitted to hospital for some time during the last phase of life and a substantial proportion of these patients eventually die in the hospital. Care in hospitals is generally focused at curing disease and prolonging life and may therefore not in all cases adequately address the needs of dying patients. Several studies have reported on shortcomings in the quality of care and unmet needs of patients dying in the hospital, which is e.g. reflected in poor symptom control, the use of aggressive treatments until shortly before dying and a lack of awareness of the approach of death.(1-4)

Involvement of palliative care experts has been shown to be associated with better outcomes for patients with advanced disease.(5) Their involvement was found to improve patients' quality of life (6-8), their satisfaction with care (8, 9) and communication about their goals of care, resulting in less diagnostic testing and less use of inappropriate technology and intensive care.(10) Studies that assess the association between consultation of palliative care expert teams (PCTs) in hospitals and QOD are scarce. In the Erasmus Medical Center, a university hospital in Rotterdam, clinical specialists can ask the multidisciplinary expert team for pain and palliative care to provide them with advice and support in their patient care. The PCT consists of palliative care nurses, a medical oncologist, a neurologist and a team of anesthesiologists and is available 24/7. The PCT focuses on symptom management, psychosocial support and medical decision making.(11) Upon their involvement, the PCT nurse performs an in-depth assessment of physical, psychosocial and spiritual needs and of the home situation. The PCT does not take over medical treatment but visits the patient daily and provides advice to the treating physician during hospitalization. If specialized psychosocial or spiritual care is needed, the PCT advises the treating physician to consult a psychologist, spiritual caregiver or social worker.

In this observational study we aim to assess whether there is an association between consultation of a PCT in a university hospital and (aspects) of QOD.

Methods

Study design and setting

Between June 2009 and July 2012, a questionnaire study was performed among relatives of patients who died in the Erasmus Medical Center, a 1300 bed general university hospital in The Netherlands. We performed a secondary analysis of data from this prospective study which assessed the quality of palliative and terminal care in the hospital, the PalTech-H-study. More information on this study can be found elsewhere.(12, 13)

Population

The study population consisted of all adult patients who died between June 2009 and July 2012 at one of the 18 non-intensive care wards in the hospital after an admission of at least 6 hours. Both expected and unexpected deaths could be included. Healthcare professionals were not involved in the selection of relatives, but had the opportunity to refuse contacting a relative, which occurred only in three cases.

10 – 13 weeks after a patient had died on a ward, a relative was invited by the primary investigator (FEW) to complete a questionnaire. In case of no response, a reminder was sent four weeks later. Relatives within a family decided who completed the questionnaire. As the PCT is mainly consulted for patients with cancer, we restricted our analysis for this paper to patients with cancer.

Questionnaire

A 93 item questionnaire was developed by an expert group to investigate QOD as perceived by relatives. The questionnaire included relevant items from validated questionnaires, including the VOICES (Views of Informal Caregivers Evaluation of Services Scale) (14) and the QODD (Quality of Death and Dying scale).(15) Questions concerned patient characteristics, characteristics of the relative (gender, age, relation to the patient, involvement of relative in care for the patient) and patients' physical and psychological symptoms during the last 3 days and the last 24 hours of life. Furthermore, the questionnaire included questions on physical, psychological, social and existential experiences, life closure, death preparation, circumstances of death and health care. Overall quality of life and QOD were assessed by asking "How would you evaluate the quality of life during the last 3 days of life of your relative?" and "How would you evaluate the quality of dying of your relative?". These questions could be answered on a 0-10 numerical scale, with 0 indicating "very poor" and 10 "almost perfect". The single item measure on QOD was used in several other studies and appeared to be associated with more extensive measures of QOD.(16-18)

Preliminary versions of the questionnaire were critically appraised by a representative of the hospital patient council and tested on relevance and face validity among four relatives of recently passed loved ones. In the first 30 cases the questionnaire was piloted and afterwards some small changes in wording were made.

Patient demographics such as date of birth and gender and underlying diagnosis were retrieved from the medical file. The PCT registry was used to identify whether patients received PCT consultation. This registry contains information on characteristics of the patients that were seen by the PCT, including reasons for consultation and patients' symptoms. In case the PCT had been involved, we extracted information from the PCT registry regarding the date of their involvement and the reasons for consulting.

Statistical analysis

The primary outcome measure in this study was QOD. Multivariable linear regression was used to assess the effect of PCT consultation QOD while adjusting for possible confounders.

Second, we assessed the effect of PCT consultation on quality of life in the last three days of life using multivariable linear regression. In order to account for possible correlation between the two main outcome variables, we performed an additional MANCOVA analysis. Third, we compared experiences of relatives of patients who died after PCT consultation and patients who died without such a consultation in a number of subdomains of QOD. We used chi-square tests to assess the statistical significance of differences between the groups. To adjust for multiple testing, we calculated adjusted p-values using the Holm-Bonferroni method.

Ethical considerations

The Medical Ethical Research Committee of the Erasmus MC approved the study. Participants were given the opportunity to contact the nurse investigator (FEW) in case of emotional distress.

Results

We received questionnaires from relatives of 175 deceased patients, out of a total of 343 patients with cancer who had died in the hospital during the study period (response 51%). PCT consultation had been provided for 77 out of these 175 patients. Relatives who filled in the questionnaire were mainly women who were the spouse or child of the deceased patient.

Characteristics of deceased patients and their relatives

Patients for whom the PCT was consulted were younger ($p=0.03$) and they more often died in a surgical ward ($p<0.01$), as compared to patients for whom the PCT was not consulted (Table 1). Patients for whom the PCT was consulted had more often been ill for over 6 months, but this difference was not statistically significant. We found no significant differences in the duration of latest hospital admission or in the degree of involvement of relatives in informal care during the last 24 hours.

Table 1: Characteristics of deceased patients and their relatives (N=175)

		Without PCT consultation **N= 98** **n (%)**	**With PCT consultation** **N= 77** **n (%)**	**P-value±**
Patients				
Gender‡	Male	57 (58)	52 (68)	0.20
	Female	41 (42)	25 (32)	
Age† (years)	Mean (sd)	69 (12.5)	65 (11.1)	0.03
Marital Status‡	Married/ living with partner	62 (66)	53 (74)	0.29
	Widowed /divorced / living alone/other	32 (34)	19 (26)	
	Missing	0	5	
Education‡	Low	30 (33)	19 (27)	0.30
	Intermediate	43 (48)	35 (49)	
	High	13 (14)	15 (21)	
	Unknown	4 (4)	2 (3)	
	Missing	8	6	
Religious‡	Yes	45 (49)	30 (42)	0.37
Duration of severe illness according to relative‡	≤ 6 Months	43 (46)	25 (34)	0.13
	>6 Months	51 (54)	48 (66)	
	Missing	5	4	
Ward‡	Nonsurgical	78 (80)	46 (60)	<0.01
	Surgical	20 (20)	31 (40)	
Relative involved in in-formal care last 24 hrs‡	Yes	81 (85)	63 (84)	0.85
	No	14 (15)	10 (16)	
	Missing	3	4	
Duration of last admission† (days)	Mean (sd)	13,5 (12,1)	13,7 (16,9)	0.93

Table 1 (continued): Characteristics of deceased patients and their relatives (N=175)

		Without PCT consultation **N= 98** **n (%)**	**With PCT consultation** **N= 77** **n (%)**	**P-value±**
Relatives				
Age† (years)	Mean (sd)	57,1 (12,7)	56,1 (12,8)	0.62
Gender‡	Male	37 (39)	25 (35)	0.58
	Female	58 (61)	47 (65)	
	Missing	3	3	
Relation‡	Partner/spouse	44 (48)	42 (60)	0.09
	Child (in law)	38 (41)	18 (26)	
	Other	10 (11)	10 (14)	
	Missing	6	7	

† T-test
‡Chi-square test
± Variables with a difference <0.10 were included in the multivariable model (see table 5)

Characteristics of PCT consultation

The main symptom for which the PCT was consulted was pain (Table 2). Pain was among the reasons to involve the PCT in 83% of all cases; other relatively common reasons were constipation or ileus (22%) and dyspnea (19%). Less frequent reasons for consulting the PCT were confusion (6%) and nausea or vomiting (5%).

In 10 cases the PCT consultation had occurred during a previous hospital admission, which took place between 16 to 296 days before the admission that ended with the patient's death. For cases in which the PCT was involved during the final admission, we assessed the time between admission and the first contact with the PCT and the time between the first contact and death. Among these cases, the PCT was consulted on the day of admission in 21% and later in the first week after admission in 55%. In 13% of all cases, the PCT was consulted more than a month before the patient's death, in 76% within the last two weeks before the patient's death, and in 9% on the day of death (Table 3).

Table 2: Reasons for consulting the Palliative Care Team (N=77)

	Reasons for consultation† n (%)	Main reason n (%)
Pain	64 (83)	55 (71)
Dyspnea	15 (19)	8 (10)
Confusion / delirium	5 (6)	1 (1)
Constipation / ileus	17 (22)	0 (0)
Nausea / vomiting	4 (5)	0 (0)
Other symptoms	12 (16)	2 (3)
Advice /starting palliative sedation	10 (13)	6 (8)
Advance care planning	8 (10)	5 (7)

†A maximum of 3 reasons for consultation was registered per consultation.

Table 3: Time between admission and consultation and time between consultation and death† (N=67)

	Time between moment of admission and first contact with the PCT n (%)	Time between first contact with the PCT and death n (%)
<1 day	14 (21)	6 (9)
1-3 days	23 (34)	18 (27)
4-7 days	14 (21)	14 (21)
8-14 days	7 (10)	13 (19)
15-30 days	4 (6)	7 (10)
31-90 days	5 (7)	7 (10)
>90 days	0 (0)	2 (3)

† For 10 patients, (the latest) PCT consultation had been provided during an admission that preceded the admission that ended with the patient's death; these patients are not included in the table.

Table 4: Symptoms, quality of life and quality of death according to relatives (N=175)

	Without PCT consultation N=98 n (%)	With PCT consultation N=77 n (%)	P-value
Moderate or severe symptoms in the last 3 days before death			
Pain	45 (62)	50 (74)	0.11‡
Fatigue	68 (85)	52 (85)	0.97‡
Dyspnea	46 (59)	36 (60)	0.90‡
Anxiety	28 (44)	22 (42)	0.87‡
Agitation	38 (50)	29 (44)	0.47‡
Moderate or severe symptoms in the last 24 hours before death			
Pain	36 (51)	37 (65)	0.11‡
Fatigue	56 (79)	43 (85)	0.92‡
Dyspnea	48 (63)	36 (63)	1.00‡
Anxiety	29 (50)	27 (64)	0.16‡
Agitation	32 (46)	33 (57)	0.24‡
Quality of life and quality of death according to relatives			
Quality of life (mean (sd))	3.72 (2.57)	3.26 (2.76)	0.28†
Quality of dying (mean (sd))	5.82 (2.73)	6.68 (2.64)	0.05†

† T-test
‡ Chi-square

Patients’ symptoms, quality of life and quality of dying

Relatives were asked to rate the patient’s symptoms during the last three days and the last 24 hours before death. Patients’ symptom burden appeared to be high. The prevalence of moderate or severe pain during the last three days of life was 74% for patients for whom the PCT was consulted compared to 62% for patients for whom the PCT was not consulted; during the last 24 hours of life these prevalences were 65% and 51%, respectively. The prevalence of moderate or severe fatigue during the last three days of life was 85% in both groups, and 85% versus 79% during the last 24 hours of life. The differences in symptom prevalence between patients for whom the PCT was and was not consulted, were not statistically significant (Table 4).

There was no significant difference in relatives’ ratings of patients’ quality of life during the last three days of life. However, their average QOD score for patients with PCT consultation was 6.7 compared to 5.8 for patients for whom the PCT was not consulted (p=0.05) (Table 4).

The multivariable regression model showed that patients for whom the PCT was consulted scored on average one point higher for QOD (95% CI=0.07-1.96) compared to patients for whom no PCT was consulted (Table 5). There was no significant association between PCT involvement and quality of life (Table 5). Based on the Wilk's lambda criterion, the combined dependent variables (QOD and quality of life) were significantly affected by the PCT consultation F (2,140) = 3.89, p =0.023. Subsequent testing showed a significant effect of PCT on QOD (F (1,141) =4.54, p=0.035) but not on quality of life (F (1,141) =0.77, p=0.381).

Table 5: Multivariable linear regression analysis assessing the effect of patient and treatment characteristics (including PCT consultation) on Quality of Dying and Quality of Life (N=150)

		Quality of Dying			Quality of life		
		B†	p-value	95% CI	B†	p-value	95% CI
PCT involvement	PCT	1.00	0.04	(0.07-1.96)	-0.52	0.25	(-1.40-0.36)
	No PCT	0			0		
Patients age		0.05	0.05	(0.00-0.09)	0.02	0.38	(-0.02-0.06)
Gender	Male	0.30	0.52	(-0.62-1.21)	-0.09	0.83	(-0.98-0.79)
	Female	0			0		
Duration of illness	< 6 months	0.30	0.52	(-0.61-1.20)	1.09	0.01	(0.24-1.95)
	>6 months	0			0		
Ward	Surgical ward	-0.03	0.96	(-1.04-0.99)	0.22	0.65	(-0.74-1.18)
	Non-surgical ward	0			0		
Relatives relation	Partner	0.57	0.42	(-0.83-1.97)	-0.62	0.35	(-1.91-0.68)
	Child	0.09	0.91	(-1.44-1.63)	-1.64	0.03	(-3.08--0.19)
	Parent	3.07	0.09	(-0.46-6.60)	-0.30	0.85	(-3.43-2.84)
	Other	0			0		

†Data represent change in QOD or quality of life, measured on a scale from 0-10.

End of life discussions, awareness and life closure

According to relatives, patients for whom the PCT was consulted scored better on several subdomains of QOD: Patients for whom the PCT was consulted had discussed their preferences for medical treatment at the end of life more often than patients for whom the PCT was not consulted, they had more often been aware of the imminence of their death, they had more often been able to say goodbye and they had more often had been at peace with their imminent death. Relatives of patients for whom the PCT was consulted had more often been aware of the imminence of the patient's death, had more often been able to say goodbye, and had more often been present at the moment of death. However, after the Holm-Bonferroni correction, these differences were not statistically significant, except for the discussion of preferences for medical care with the general practitioner (Table 6).

Table 6: End of life discussions, awareness and life closure according to relatives (N =175)

		Without PCT consultation n (%)	With PCT consultation n (%)	X^2	P value†
Patient had discussed preferences for medical treatment at end of life with somebody.	Yes	57 (62)	59 (82)	7.79	0.070
	No	35 (38)	13 (18)		
	Missing	6	5		
Patient had discussed preferences for medical treatment at end of life with family	Yes	58 (59)	60 (78)	6.89	0.117
	No	40 (41)	17 (22)		
	Missing	0	0		
Patient had discussed preferences for medical care at end of life with a GP	Yes	15 (16)	27 (38)	9.52	0.030
	No	77 (84)	45 (62)		
	Missing	6	5		
Patient had discussed preferences for medical care at end of life with a medical specialist	Yes	24 (26)	27 (38)	2.46	0.468
	No	68 (74)	45 (62)		
	Missing	6	5		
Patient had discussed preferences for medical care at end of life with a nurse	Yes	6 (7)	9 (13)	1.74	0.564
	No	86 (93)	63 (87)		
	Missing	6	5		

Table 6 (continued): End of life discussions, awareness and life closure according to relatives (N =175)

		Without PCT consultation	With PCT consultation		
		n (%)	**n (%)**	**X^2**	**P value†**
Preferences were met?	Yes	12 (48)	13 (52)	0.108	1.000
	No	45 (52)	42 (48)		
	Missing	41	22		
Would the relatives preferred to have more discussions on preferences and medical treatment?	Yes	23 (26)	23 (32)	1.02	1.000
	No	48 (53)	33 (46)		
	DK*	19 (21)	15 (21)		
	Missing	8	6		
Patient was aware of imminent death	Yes	20 (22)	28 (39)	7.02	0.270
	No	60 (64)	32 (45)		
	DK	13 (14)	11 (16)		
	Missing	3	4		
At what moment was the patient aware of imminent death?	>72h	7 (13)	20 (35)	7.95	0.216
	<72h	32 (59)	28 (49)		
	DK	15 (28)	9 (16)		
	Missing	44	20		
Patient was able to say goodbye	Yes	38 (40)	39 (56)	8.03	0.216
	No	55 (59)	27(39)		
	DK	1 (1)	4 (6)		
	Missing	4	7		
Patient was at peace with imminent death	Yes	34 (38)	42 (57)	6.81	0.297
	No	28 (31)	18 (25)		
	DK	28 (31)	13 (18)		
	Missing	8	4		
Relative was aware of imminent death	Yes	37 (40)	43 (59)	6.01	0.322
	No	53 (58)	28 (38)		
	DK	2 (2)	2 (3)		
	Missing	6	4		
At what moment was the relative aware of imminent death?	>72h	20 (32)	30 (48)	3.35	0.335
	<72h	42 (68)	32 (52)		
	Missing	36	15		

Table 6 (continued): End of life discussions, awareness and life closure according to relatives (N =175)

		Without PCT consultation n (%)	With PCT consultation n (%)	X²	P value†
Relative said goodbye to patient	Yes	44 (46)	44 (62)	4.00	0.322
	No	51 (54)	27 (38)		
	Missing	3	6		
Relative was present at moment of death	Yes	71 (75)	63 (88)	4.21	0.320
	No	24 (25)	9 (12)		
	Missing	3	5		

† P-values were calculated using the Holm-Bonferroni method

*DK=don't know

Hospital care during the last days of life

Several aspects of hospital care were investigated, such as efforts to alleviate symptoms, social support and patients' and relatives' participation in medical decision making. We did not find statistically significant differences between patients for whom the PCT was or was not consulted (Table 7).

64% of relatives of patients for whom the PCT was consulted stated that there had been sufficient opportunity to discuss religious preferences, compared to 53% of relatives of patients without consultation. No significant differences were found regarding the provision of information, attention for preferred rituals at the moment of dying or affirmation of the patient as a whole person.

Table 7: Hospital care in the last days of life according to relatives (N = 175)

		Without PCT consultation n (%)	With PCT consultation n (%)	X²	P value†
Efforts to alleviate symptoms and problems last 3 days before death were sufficient	Yes	51 (56)	43 (61)	3.89	1.000
	No	7 (8)	9 (13)		
	Partly	20 (22)	8 (11)		
	NA*	10 (11)	8 (11)		
	DK**	3 (3)	3 (4)		
	Missing	7	6		

Table 7 (continued): Hospital care in the last days of life according to relatives (N = 175)

		Without PCT consultation **n (%)**	**With PCT consultation** **n (%)**	**X²**	**P value†**
Efforts to alleviate symptoms and problems last 24 hours before death were sufficient	Yes	62 (77)	48 (71)	0.53	1.000
	No	9 (10)	7 (10)		
	Partly	13 (15)	10 (15)		
	DK	2 (2)	3 (4)		
	Missing	12	9		
Social support the last 3 days before death were sufficient	Yes	49 (54)	32 (46)	4.28	1.000
	No	11 (12)	15 (21)		
	Partly	12 (13)	13 (19)		
	NA	11 (12)	7 (10)		
	DK	7 (8)	3 (4)		
	Missing	8	7		
Social support the last 24 hours before death were sufficient	Yes	54 (61)	43 (66)	3.66	1.000
	No	10 (11)	10 (15)		
	Partly	17 (19)	11 (17)		
	DK	7 (8)	1 (2)		
	Missing	10	12		
In the last days of life, **patient** participated sufficiently in decision making on medical treatment	Yes	45 (52)	34 (50)	0.14	1.000
	No	14 (16)	10 (15)		
	Sometimes	15 (17)	13 (19)		
	DK	14 (16)	11 (16)		
	Missing	10	9		
In the last days of life, **relative** participated sufficiently in decision making on medical treatment	Yes	65 (74)	47 (67)	0.97	1.000
	No	17 (19)	18 (26)		
	DK	6 (7)	5 (7)		
	Missing	10	7		
Did the relative receive sufficient information in the last days before death?	Yes	66 (73)	51 (72)	1.60	1.000
	Too much	1 (1)	3 (4)		
	Too little	23 (26)	17 (24)		
	Missing	8	6		

Table 7 (continued): Hospital care in the last days of life according to relatives (N = 175)

		Without PCT consultation **n (%)**	**With PCT consultation** **n (%)**	**X²**	**P value†**
Information that was given to the relative was understandable	Yes	71 (79)	49 (68)	2.71	1.000
	No	1 (1)	1 (1)		
	Partly	12 (13)	13 (18)		
	No info	6 (7)	9 (13)		
	Missing	8	5		
Relatives were informed about imminent death	Yes	53 (58)	46 (64)	0.54	1.000
	No	38 (42)	26 (36)		
	Missing	7	5		
Opportunity to discuss personal or religious preferences was sufficient	Yes	46 (53)	45 (64)	6.536	0.532
	No	15 (17)	16 (23)		
	DK	26 (30)	9 (13)		
	Missing	11	7		
Attention was paid to personal or religious preferences	Yes	47 (51)	40 (56)	2.60	1.000
	No	7 (8)	10 (14)		
	DK	35 (39)	21 (29)		
	Missing	9	6		
Attention to preferred rituals at the moment of death was sufficient	Yes	40 (49)	36 (58)	3.67	1.000
	No	8 (10)	10 (16)		
	DK	34 (41)	17 (27)		
	Missing	16	14		
Affirmation of the patient as a whole person was sufficient	Yes	56 (61)	40 (58)	2.02	1.000
	No	8 (9)	6 (9)		
	Partly	19 (12)	12 (17)		
	DK	8 (9)	11 (16)		
	Missing	7	8		
Attention to wishes of patient and relatives in the days before death was sufficient	Yes	63 (70)	55 (77)	2.30	1.000
	No	7 (8)	6 (9)		
	Partly	11 (12)	7 (10)		
	DK	9 (10)	3 (4)		
	Missing	8	6		

† P-values were calculated using the Holm-Bonferroni method

*NA=Not applicable

** DK= Don’t know

Discussion

In this observational study we found an association between involvement of a hospital-based PCT and QOD in patients with cancer. Patients for whom the PCT was or was not consulted were comparable regarding gender, marital status, education, duration of the illness and duration of the latest hospital admission. Patients for whom the PCT was consulted were younger and more often admitted to a surgical ward than patients for whom the PCT was not consulted. In a nationwide Dutch study, it was also found that patients for whom a PCT is consulted are often younger compared to patients for whom the PCT is not consulted.(19) Involvement of the PCT mostly occurred rather late in the disease trajectory: in 76% of all cases the first contact with the PCT occurred within two weeks before death. From other studies it is known that late referral to a PCT is common (20-22), although late referral may decrease the effect of PCT involvement.(23)

The mean QOD score according to relatives for patients for whom the PCT was consulted was 6.7 compared to 5.8 for patients without PCT consultation. This difference remained significant when taking into account potential confounders in a multivariable regression model. This is comparable to an Italian study in which the effect of the Liverpool Care Pathway (LCP) on quality of care for patients with cancer who are dying in the hospital was studied. This study reported a mean score of quality of care at the end of life of 70,5 on a 0-100 scale for patients who died at a ward where the LCP was implemented, compared to a score of 63 for patients on the control wards.(24)

QOD is a multidimensional construct that has been suggested to include physical, psychological, social and spiritual aspects, and issues related to life closure, death preparation and circumstances of death and characteristics of health care at the end of life.(25) We found a non-significant trend towards a more favorable outcome for patients for whom the PCT was consulted such as more discussion of preferences for medical treatment at the end of life, more and earlier awareness of impending death (both in patients and relatives) and more patients being at peace with their imminent death. Relatives were more often able to say goodbye to the patient and more often present at the moment of death. However, these associations were not statistically significant. In other studies, it was found that no or late specialized palliative care involvement is associated with worse death preparation (26) and decreased disease awareness of terminally ill patients.(27)

We did not find a statistically significant difference in quality of the last three days of life. In several other studies, positive effects of PCT involvement on patients' quality of life were found. In these studies, contrary to our study, the PCT was involved relatively early in patients' disease trajectory and quality of life was not assessed during the last days before death.(6, 28, 29)

The PCT was mainly consulted for physical symptoms; the most frequently mentioned reason for involving the PCT was pain, followed by dyspnea, which is also in line with other studies.(30-32) The PCT that was studied always performs a multidimensional assessment of the patient's condition and needs, even if the initial reason for consulting the PCT is related to pain problems. The PCT assesses physical, social, psychological and spiritual problems and discusses these with the treating physician. We found no significant differences in the severity of patients' symptoms during the days before death. As we did not conduct before and after measurements of symptoms, we cannot draw any conclusions on the impact of involvement of the PCT on symptom burden. Nevertheless, symptom burden in patients for whom the PCT was consulted may have been higher at admission compared to patients for whom the PCT was not consulted, as pain was often the reason for consulting the PCT. Furthermore, in 38% of consultations, the PCT was consulted within the last 3 days of life, which may represent a timeframe that is too short to have a significant impact on symptoms. Finally, involvement of the PCT can also be related to a specialist's awareness of the availability of the PCT or their willingness to consult the PCT.(33)

Limitations

The explorative nature of this study implies that we cannot draw strong conclusions about the causal relation between the involvement of PCT and aspects of QOD. There may be other factors besides the involvement of the PCT that account for the differences in QOD that were found in this study, such as prior awareness and communication and confounding by indication. Second, as we performed a secondary analysis of existing data, the power of the study may have been insufficient to detect statistically significant differences between both groups. Furthermore, this study is restricted to the perspectives of the relatives. From other research it is known that perspectives of relatives can differ from those of the patient or the physician.(34) We did not have information on the non-responders, so selection bias cannot be ruled out. As this study was performed in a single, academic centre, the generalizability of the findings may be limited.

Conclusion

In this study, we found that PCT consultation was associated with a favorable QOD for patients with cancer who died in the hospital. Our results suggest that PCT involvement has positive effects on patients’ and relatives’ awareness of death.

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CHAPTER 7

Palliative care in Dutch hospitals: a rapid increase in the number of expert teams, a limited number of referrals

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Abstract

Background

Palliative care expert teams in hospitals have positive effects on the quality of life and satisfaction with care of patients with advanced diseases. Involvement of these teams in medical care is also associated with substantial cost savings. In the Netherlands, professional standards state that each hospital should have a palliative care team by 2017. We studied the number of hospitals that have a palliative care team or other palliative care services, and the characteristics of these teams.

Methods

In April 2015, questionnaires were mailed to key palliative care professionals in all general, teaching and academic hospitals in the Netherlands. Out of 92 hospitals, 74 responded (80%).

Results

Seventy-seven percent of all participating hospitals had a palliative care team. Other services, such as outpatient clinics (22%), palliative care inpatient units (7%), and palliative day care facilities (4%) were relatively scarce. The mean number of disciplines that were represented in the teams was 6,5. The most common disciplines were nurses (72%) and nurse practitioners (54%), physicians specialized in internal medicine (90%) or anaesthesiology (75%) and spiritual caregivers (65%). In most cases, the physicians did not have labeled hours available for their work as palliative care consultant, whereas nurses and nurse practitioners did. Most teams (77%) were only available during office hours. Twenty-six percent of the teams could not only be consulted by health care professionals but also by patients or relatives. The annual number of consultations for inpatients per year ranged from 2 to 680 (median: 77). On average, teams were consulted for 0.6% of all patients admitted to the hospitals.

Conclusion

The number of Dutch hospitals with a palliative care team is rapidly increasing. There are substantial differences between teams regarding the disciplines represented in the teams, the procedures and the number of consultations. The development of quality standards and adequate staffing of the teams could improve the quality and effectiveness of the teams.

Background

In the Netherlands, palliative care is an integral part of regular healthcare. Dutch government policy is based on the idea that palliative care is generalist care and should therefore be provided by all healthcare professionals whenever necessary. As such, palliative care is not a distinct medical specialty as it is in many other countries. Core elements of palliative care, such as basic symptom management and aligning treatment with patients' goals, should be integrated in care as it is delivered by any healthcare professional. In case of complex problems, such as managing refractory symptoms or negotiating a difficult family meeting, specialist palliative care should be available. Palliative care teams (PCTs) can be consulted by professionals involved in palliative care and can provide such specialist palliative care, either in or outside the hospital.

This model of palliative care delivery resembles the model as described by Quill and Abernethy (1) which distinguishes primary palliative care (which includes skills all clinicians should have) and specialist palliative care (which includes skills for managing more complex and difficult problems).(1) In the Netherlands, PCTs are available throughout the country since the start of this century. Currently, 30 regional PCTs are mainly consulted by general practitioners, nursing home physicians and home care nurses, but not by hospital-based care professionals.(2) In the Netherlands, two thirds of patients with advanced incurable disease are admitted to hospital at some time during their last three months of life.(3) Of cancer patients older than 65 years, 29% dies in hospital, a percentage that is low compared to other countries.(4) Hospital care is usually focused on diagnosis, treatment and discharge, and several studies have reported unmet needs and deficiencies in the quality of care of patients dying in the hospital.(5-7) PCTs in hospitals have been shown to have positive effects on patients' quality of life and satisfaction with care.(8-11) In order to improve hospital palliative care, the Dutch Federation of Oncological Societies (SONCOS) has stated in their "Multidisciplinary standards for oncological care in the Netherlands" that each hospital should have a PCT by 2017.(12) This development underlines the important role PCTS are expected to play in supporting professional caregivers and in providing specialized palliative care.

The aim of this study is to investigate the number of hospitals that currently have a PCT and to study the characteristics of these teams.

Methods

Study design and data collection

In April 2015 we performed a cross-sectional study. An online questionnaire was sent to key professionals in palliative care in all 92 general, teaching and university hospitals in the Netherlands, including two oncology centers. The key persons were care professionals who are known to have an important role in the development of palliative care in their hospital. In case of non-response, these persons were contacted after several weeks by mail or phone to remind them of the study and to invite them to fill in the questionnaire.

Population and setting

In total, 74 questionnaires were returned (response rate of 80%); responses came from general hospitals (n=43), teaching hospitals (n=23) university hospitals (n=7) and one oncology hospital. Non-responding hospitals included both hospitals with and without PCTs.

Questionnaire

The key professionals were requested to fill out a 78 item questionnaire which was based on a questionnaire from a former study.(13) It was pretested by two PCT members. Based upon this test, the wording of some questions was improved. After an introduction and some general questions on the provision of palliative care in their hospital, the questionnaire focused on the PCT, if applicable. Questions were asked about the disciplines that were represented in the PCT, the procedures followed by the team, the number of consultations, team meetings and quality assurance procedures.

Statistical analysis

We analyzed the data using SPSS version 20.

Results

Palliative care in hospitals

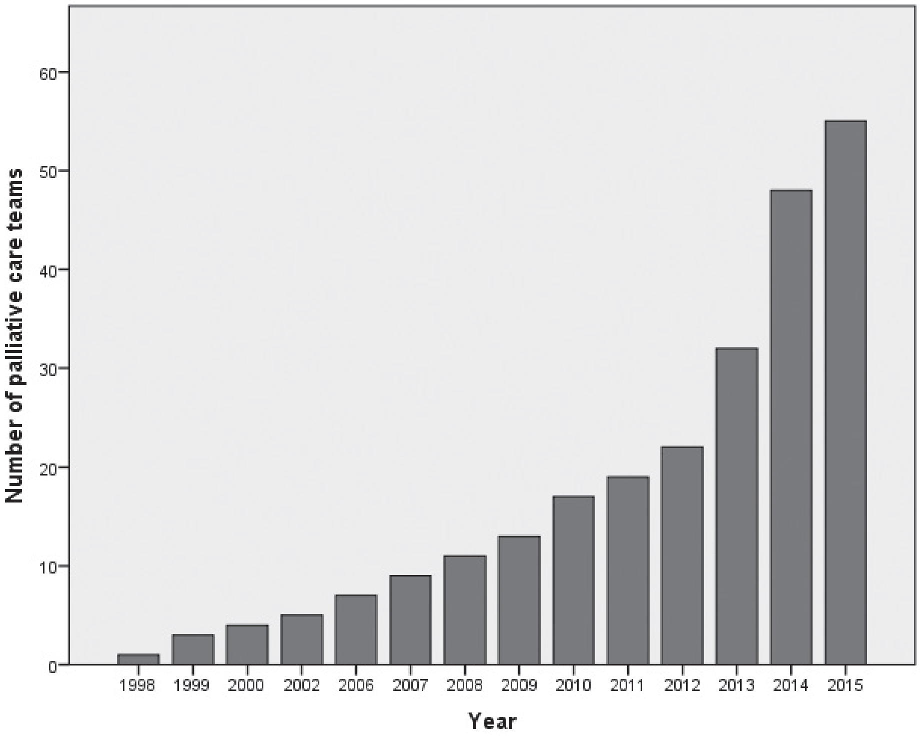
Palliative care is on the agenda of most hospitals (Table 1). The majority of hospitals has an assignment from the board of directors or medical staff to develop palliative care (82%) or has a steering committee implementing palliative care (85%). Fifty-four percent of all hospitals have a palliative care policy of some form. Overall, 77% of hospitals have a PCT and the other 23% are in the process of starting one. The number of teams has

increased rapidly over the last 3 years (Figure 1). Other palliative care facilities, such a labeled palliative care beds (20%), inpatient units for palliative care (7%), outpatient palliative care clinics (22%) and palliative daycare facilities (4%) are relatively scarce.
A vast majority of all hospitals use measurement instruments (91%) to assess symptom burden. Most frequently used instruments are the Distress Thermometer (73%), Numeric Rating Scales (NRS) / Visual Analogue Scales (VAS) (24%) and the Utrecht Symptom Diary / Edmonton Symptom Assessment Scale (ESAS) (18%). Respondents remarked that these instruments and guidelines are often not used throughout all hospital wards. Ninety-six percent of hospitals follow national palliative care guidelines, although respondents remarked that not every healthcare professional is familiar with these guidelines. Seventy-three percent of all hospitals have one or more wards with nurses that have palliative care as their special field of interest and education.

Table 1: Hospital characteristics (N=74)

	Overall N=74 n (%)
Number of beds	
- 0-500	47 (63)
- 501-1500	25 (34)
- Missing	2 (3)
Palliative care policy plan	40 (54)
Assignment from the board of directors or medical staff to develop palliative care	61 (82)
Palliative care steering group	63 (85)
Palliative Care Team	57 (77)
Number of PCTs that started before 2012	19 (34)
Number of PCTs that started before 2010	13 (25)
Outpatient clinic palliative care	16 (22)
Palliative daycare	3 (4)
Palliative care labeled beds	15 (20)
Labeled beds are concentrated on a unit for palliative care	5 (7)
Palliative care nurse champions	54 (73)
Use of measurement instruments	67 (91)
Use of palliative care guidelines	71 (96)
Use of care pathway for the dying	52 (70)

Figure 1: Number of hospitals with palliative care consultation teams (N=55*)



*For two hospitals the start date is missing

Palliative care teams

Number of consultations

In 2014, 50 out of the 74 hospitals had a PCT. The annual number of inpatient consultations per team ranged between 2 and 680, with a median number of 77.

PCTs that started before 2012 have substantially more consultations (median 160 consultations) compared to PCTs that started after 2012 (median 39 consultations).

PCTs in university hospitals have more referrals compared to PCTs in general and teaching hospitals. PCTs in university hospitals tend to have started earlier compared to teaching and general hospitals. There are no other differences between different types of hospitals. All PCTs can be consulted for inpatients, but only 28 teams can also be consulted at the outpatient clinic, with a median annual number of consultations for outpatients of 20 (range 2-384). Ten teams were willing to visit patients at home with a median annual number of 6 home visits (range 1-74). Twenty-four percent of the respondents stated that the number of consultations exceeds their capacity; 47%

stated that the number of consultations is less than their capacity. The annual number of palliative care consultations for inpatients as a percentage of the total annual number of hospital admissions ranged between 0.01% and 2.3% with a mean of 0.6%.

Disciplines represented in the PCT

The most common disciplines are nurses (72%) and nurse practitioners (54%), physicians specialized in internal medicine (90%) or anesthesiology (75%) and spiritual caregivers (65%). Both psychologists and social workers participate in 28% of the teams (Attachment 1). In the majority of teams, nurses and nurse practitioners have labeled hours for their work as a palliative care consultant. However, the majority of medical specialists, social workers and spiritual caregivers have no labeled hours. For the minority that does, the mean number of hours varies between 1 and 4 h per week. About one third of the teams include a general practitioner and another third includes a nursing home physician.

Procedures followed by the PCT

Table 2 describes characteristics of the procedures followed by the PCT. All teams can be consulted by medical specialists, 79% can be consulted by nurses, 40% by paramedics and 26% by patients or relatives. Eleven percent of the PCTs is available 24/7. Most consultations involve face to face contact of the PCT with the patient (81%). Seventy-two percent of all teams have explicit referral criteria. There are different types of transmural collaboration. In about half of the cases (54%) the PCT consists of professionals both from inside and outside the hospital. Most teams are involved in other activities such as palliative care education inside (95%) and outside (51%) the hospital, development of protocols (81%) and scientific research (33%). A vast majority of teams (95%) has a weekly multidisciplinary team meeting to discuss patients that were referred to them (Table 3).

Table 2: Characteristics of the procedure followed by the palliative care team (N=57)

	Overall **N =57** **n (%)**
The team has specified referral criteria	41 (72)
Who can consult the PCT?	
- Medical specialist	57 (100)
- Co-assistant	24 (42)
- Paramedics	23 (40)
- Nurses	45 (79)
- Patients and/or relatives	15 (26)
For which type of patients can the PCT be consulted?	
- Clinical patients	57 (100)
- Patients at the outpatient clinic	35 (62)
- Patients who are known by the PCT and who are staying at home	29 (51)
- Patients who are not known by the PCT and who are staying at home	13 (23)
Availability of the PCT	
- During office hours	51 (89)
- 24 hours / 7 days a week	6 (11)
The advice is given:	
- Mostly bedside	46 (81)
- Mostly face to face with referring professional	40 (70)
- Mostly by telephone	16 (28)
Is there a standard follow up of the patient?	
- Mostly	28 (49)
- Sometimes	26 (46)
- Never	3 (5)
Is there a standard follow up with the referring professional?	
- Mostly	30 (53)
- Sometimes	27 (47)
Is there standard deliberation with the transfer nurse about the situation at home?	
- Yes, always	4 (25)
- On indication	37 (65)
- No	6 (11)

Table 2 (continued): Characteristics of the procedure followed by the palliative care team (N=57)

	Overall N =57 n (%)
Is there standard deliberation with the general physician – nursing home physician before discharge?	
- Yes, always	15 (26)
- On indication	30 (53)
- No	12 (21)
Members of the PCT visit patients at home	13 (23)
Forms of out-patient / in home collaboration	
- The PCT consists of professionals both form inside and outside the hospital	31 (54)
- The PCT provides consultation by telephone for patients who reside outside the hospital	19 (33)
- The PCT provides bedside consultation outside the hospital	11 (19)
- Consultants from regional PCTs' perform bedside consultation in the hospital	5 (9)
- The PCT does not work transmural	13 (23)
Other activities of the PCT	
- Scientific research	19 (33)
- Education inside the hospital	54 (95)
- Education outside the hospital	29 (51)
- Development of protocols	46 (81)

Table 3: Characteristics of the palliative care consultation teams meetings (N=57)

	Overall N=57 n (%)
The frequency of the PCT's meetings is at least once a week	54 (95)
Is the persons who request the consultation present at the PCT's meeting?	
- Always /often	15 (26)
- Sometimes / seldom /never	42 (74)
Which type of patients are discussed at the meeting?	
- All patients	26 (46)
- Only complex patients	6 (11)
- Only new patients	5 (9)
- Only new and complex patients	20 (35)
A report with the PCT's advice is sent to the general practitioner / nursing home physician	30 (53)
A report with the PCT's advice is sent to the person who requested the consultation	43 (75)
Members of the PCT are present at multidisciplinary team meetings of other hospital departments.	33 (56)

Quality aspects

Most teams make use of national palliative care guidelines and measurement instruments (90%) (Table 4). The measurement instrument used most often by the PCT is the Distress Thermometer (56%).

Sixty-five percent of the PCTs have defined quality criteria for providing their advice. The most frequently defined criterion is that the PCT advice is given within 24 h. Ninety-one percent of PCTs has specified some requirements regarding the PCT members' expertise. However, a broad range of educational programs is mentioned and there is no consensus regarding the required education for each participating discipline.

Table 4: Quality aspects of the palliative care team (N=57)

	Overall N=57 n (%)
The PCT uses guidelines and measurement instruments	51 (90)
The PCT has specified quality criteria	37 (65)
The PCT has set criteria regarding the education of team members	52 (91)
There is education for the team as a whole	30 (53)
Attention is paid to 'care for carers'*	35 (61)
There are team meetings for issues not concerning patientcare	
- Yes, regularly	27 (46)
- Yes, incidentally	29 (51)
- No	1 (2)

*Care for carers refers to caring for the healthcare professional

Supporting and impeding factors for the development and implementation of the PCT
Respondents were asked to mention factors that either supported or impeded the development and implementation of the team. The most frequently mentioned supportive factors where enthusiasm and motivation of the PCT members, including a role of 'ambassador' fort the team of nurses and nurse practitioners (46%), aspects regarding functioning of the team (e.g. accessibility and availability of the team, response to referrals and educational activities) (47%), receiving (financial) support from the hospital management (22%) and satisfaction of patients and referring physicians who acknowledge the added value of the team (16%). Impeding factors for successful development of a PCT are lack of finances (77%), lack of commitment and/or financial support by the hospital management (19%), lack of awareness regarding the existence of the PCT (18%) and a (negative) attitude of some medical specialists and nurses towards the PCT (18%). Some respondents (5%) mentioned late referral to the PCT as an impeding factor.

Discussion

The awareness of palliative care in Dutch hospitals is increasing. A vast majority of hospitals has an assignment from the board of directors or medical staff to develop palliative care or a palliative care steering committee. The percentage of hospitals with a PCT has risen from 39% in 2013 (13) up to 77% in 2015. In all likelihood, the norms set by the Dutch Federation of Oncological Societies (SONCOS), which state that each hospital should have a PCT by January 2017, contributed to the substantial increase in numbers of teams.(12)

As positive as this increase in number of PCTs may be, the characteristics of the PCTs also show us substantial differences between the teams. Teams that started before 2012 have substantially more referrals than 'younger' teams. It is known that the establishment of a PCT takes time. In the literature, many barriers to consultation have been described. These include misconceptions that palliative care is only appropriate for patients nearing death or that involving palliative care professionals can be conceived by patients as a sign that there is no hope left.(14, 15) Because of these misconceptions PCTs are often consulted late in the disease trajectory.(15-19)

In studies that show positive effects of PCTs, these teams are often consulted relatively early in a patient's disease trajectory, and often in the outpatient clinic.(8, 11, 20) While the percentage of hospitals with palliative care outpatient clinics rose from 11% in 2013 to 22% in 2015 (13), still less than a quarter of hospitals offers their patients this opportunity for early palliative care support.

Besides differences in the number of consultations, there are also differences in the working processes of the teams, in disciplines participating in the teams, in the expertise teams require from their members and in the availability of the team and involvement in care for out-patients. Furthermore, there is no consensus regarding the use of measurement instruments. Non-specialized care professionals in hospitals as well as PCTs use a wide variety of measurement instruments. In this survey, most commonly used by both generalists and specialists in palliative care is the Distress Thermometer, an instrument originally validated as a screening tool for psychological distress, that is now also used to screen for referral to a PCT.(21, 22)

In a 1-day observational study in 14 Belgian hospitals, it was found that 9,4% of all patients admitted to the hospital are in the palliative phase, which was defined as the phase where a patient suffering from an incurable, progressive, life-threatening disease, without a prospect of remission, stabilization or improvement.(23) A study by Gardiner et al. in two acute hospitals in the UK showed that 36% of all hospitalized adult patients were identified as having palliative care needs according to the Gold Standards Framework criteria (criteria that support professionals to identify patients who are nearing the end of life and to assess their needs, symptoms and preferences (24), whereas medical staff identified 15.5% of patients as having palliative care needs.(25) In our survey we found that the annual number of palliative care consultations as a percentage of the total annual number of hospital admissions, was 0.6%. This is low compared to other countries such as the United States where an average rate of 4,4% was found.(26) This implies that more patients in hospitals could benefit from specialist palliative care.

Furthermore, the number of labeled hours that members of the PCTs have for their work as an expert palliative care consultant, is very low, especially for physicians. This in line with a recent report of the Economic Intelligence Unit on the Quality of Death Index. All though the Netherlands are ranked 8th on the overall score and 2nd on palliative care and health care environment, the score on human resources is relatively low (22nd). This means that the availability of specialists in palliative care and health care professionals with general knowledge of palliative care is low, as is the availability of appropriate training.(27) This is confirmed by the lack of adequate financing of the PCTs in hospitals in our study.

Dumanovsky et al. conclude that higher staffing levels (full-time equivalents of PCT members per 10.000 admissions) were associated with higher service penetration (the annual number of palliative care consultations as a percentage of the total annual number of hospital admissions). In their study, palliative care programs with the highest staffing levels (≥ 2.7 FTE per 10.000 admissions) reached a service penetration of 6,5%. Higher service penetration was associated with shorter time to the initial palliative care consultation.(26)

Strengths and limitations

This nationwide study demonstrates the increasing number of PCTs in the Netherlands. It demonstrates variations between the number of referrals and working procedures of the teams. The results can have implications for the development of new (models for) PCTs. A strength of this study is the relatively high response rate. Among the non-responders were both hospitals with and without PCTs. Therefore, we can conclude that this study gives a good overview of current palliative care practices in Dutch hospitals.

A limitation is that our study does not give insight in the quality of palliative care in Dutch hospitals or in the quality of the PCT involvement. From a recent comparison between different countries, using data from 2010, it was found that end-of-life care in the Netherlands is characterized by a relatively low percentage of hospital deaths, a low percentage of intensive care admissions and a low use of chemotherapy in the last 180 days before death.(4) This suggests that there may be a relatively high awareness among Dutch health care professionals of the need to refocus care when the end of life approaches, although no firm conclusions can be drawn based on these data regarding the quality of palliative care in Dutch hospitals. We recommend further studies to monitor the development of these PCTs and to gain more insight in the timing and the quality of palliative care team involvement in Dutch hospital.

Conclusion

Palliative care in Dutch hospitals is often supported by PCTs. The number of these teams has rapidly increased over the last few years, but there are substantial differences between teams regarding the disciplines represented in the teams, the procedures and the number and timing of referrals. The involvement of PCTs in care for incurably ill patients is relatively limited.

To stimulate the further development and implementation of PCTs in hospitals, we recommend the development of a formalized quality framework with models for (transmural) palliative care team consultation, to improve the quality of palliative care in hospitals. Such a framework, that should by adopted by professional organizations and policymakers, can form the basis for the development of quality criteria and quality assessment of PCTs. The concepts and borders of generalist and specialist palliative care should be discussed and where possible defined, so that criteria can be set regarding the education of all disciplines involved. Furthermore, adequate staffing of the PCTs is necessary to increase the number of PCT consultations.

Acknowledgements

The authors thank the palliative care key persons in the hospitals for filling in the questionnaire.

Attachment 1: Disciplines represented in the palliative care consultation teams (N=57)

	All n (%)	Labeled hours per week - n
Nurse*	41 (72)	
- Nurses without labeled hours	– 8 (20)	
- Nurses with labeled hours	– 33 (80)	1-2: 4
		3-8: 4
		9-20: 10
		21-40: 7
		>40: 8
Nurse practitioner	31 (54)	
– Nurse practitioners without labeled hours	– 6 (22)	
– Nurse practitioners with labeled hours	– 23 (78)	1-2: 2
		3-8: 3
		9-20: 5
		21-40: 11
		>40: 2
Anesthesiologist	43 (75)	
– Anesthesiologists without labeled hours	– 25 (61)	
– Anesthesiologists with labeled hours	– 16 (39)	1-2: 11
		3-8: 4
		9-20: 1
		21-40: -
		>40: -
Internal medicine specialist	51 (90)	
– Internal medicine specialists without labeled hours	– 29 (62)	
– Internal medicine specialists with labeled hours	– 18 (38)	1-2: 7
		3-8: 7
		9-20: 2
		21-40: 1
		>40: 1
Radiotherapist	15 (26)	
– Radiotherapists without labeled hours	– 11 (85)	
– Radiotherapists with labeled hours	– 2 (15)	1-2: 1
		3-4: 1
		9-20: -
		21-40: -
		>40: -

Attachment 1 (continued): Disciplines represented in the palliative care consultation teams (N=57)

	All n (%)	Labeled hours per week - n
Lung specialist	33 (58)	
– Lung specialists without labeled hours	– 22 (73)	
– Lung specialists with labeled hours	– 8 (27)	1-2: 6 3-8: 1 9-20:1 21-40: - >40: -
Clinical geriatrician	27 (47)	
– Clinical geriatricians without labeled hours	– 14 (63)	
– Clinical geriatricians with labeled hours	– 8 (37)	1-2: 5 3-8: 3 9-20: - 21-40: - >40: -
Nursing home physician	18 (32)	
– Nursing home physicians without labeled hours	– 6 (40)	
– Nursing home physicians with labeled hours	– 9 (60)	1-2: 5 3-8: 2 9-20: 2 21-40: - >40: -
General practitioner	19 (33)	
– General practitioner s without labeled hours	– 6 (38)	
– General practitioners with labeled hours	– 10 (62)	1-2: 8 3-8: 2 9-20: - 21-40: - >40: -
Spiritual counselor	37 (65)	
– Spiritual counselors without labeled hours	– 21 (64)	
– Spiritual counselors with labeled hours	– 12 (36)	1-2: 9 3-8: 2 9-20: 1 21-40: - >40: -

Attachment 1 (continued): Disciplines represented in the palliative care consultation teams (N=57)

	All n (%)	Labeled hours per week - n
Psychologist	16 (28)	
– Psychologists without labeled hours	– 14 (93)	
– Psychologists with labeled hours	– 1 (7)	1-2: 1 3-8: - 9-20: - 21-40: - >40: -
Social worker	17 (28)	
– Social workers without labeled hours	– 14 (82)	
– Social workers with labeled hours	– 3 (18)	1-2: 2 3-4: 1 9-20: - 21-40: - >40: -
Mean number of disciplines participating in the teams (sd)		6,5 (2,4)

*nurses include oncology nurses, pain nurses, palliative care nurses

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CHAPTER 8

Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey

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Abstract

Background

In 2002, the euthanasia act came into effect in the Netherlands, which was followed by a slight decrease in the euthanasia frequency. We assessed frequency and characteristics of euthanasia, physician-assisted suicide, and other end-of-life practices in 2010, and assessed trends since 1990.

Methods

In 1990, 1995, 2001, 2005, and 2010 we did nationwide studies of a stratified sample from the death registry of Statistics Netherlands, to which all deaths and causes were reported. We mailed questionnaires to physicians attending these deaths (2010: n=8496 deaths). All cases were weighted to adjust for the stratification procedure and for differences in response rates in relation to the age, sex, marital status, region of residence, and cause and place of death.

Findings

In 2010, of all deaths in the Netherlands, 2.8% (95% CI 2.5–3.2; 475 of 6861) were the result of euthanasia. This rate is higher than the 1.7% (1.5–1.8; 294 of 9965) in 2005, but comparable with those in 2001 and 1995. Distribution of sex, age, and diagnosis was stable between 1990 and 2010. In 2010, 77% (3136 of 4050) of all cases of euthanasia or physician-assisted suicide were reported to a review committee (80% [1933 of 2425] in 2005). Ending of life without an explicit patient request in 2010 occurred less often (0.2%; 95% CI 0.1–0.3; 13 of 6861) than in 2005, 2001, 1995, and 1990 (0.8%; 0.6–1.1; 45 of 5197). Continuous deep sedation until death occurred more frequently in 2010 (12.3% [11.6–13.1; 789 of 6861]) than in 2005 (8.2% [7.8–8.6; 521 of 9965]). Of all deaths in 2010, 0.4% (0.3–0.6; 18 of 6861) were the result of the patient's decision to stop eating and drinking to end life; in half of these cases the patient had made a euthanasia request that was not granted.

Interpretation

Our study provides insight in consequences of regulating euthanasia and physician-assisted suicide within the broader context of end-of-life practices. In the Netherlands the euthanasia law resulted in a relatively transparent practice. Although translating these results to other countries is not straightforward, they can inform the debate on legalization of assisted dying in other countries.

Introduction

At the end of life, many patients need comfort-oriented care. Such care may include end-of-life decision making (eg, on forgoing burdensome treatment or intensifying alleviation of pain or other symptoms). During this period, people can even develop a death wish, when suffering becomes overwhelming.(1,2) Patients may then ask their physician to end their life. In most countries physicians are not allowed to grant such a request, but there is much debate on this issue.(3-6) Concerns expressed include the fear of an expanding practice of euthanasia (eg, among vulnerable groups such as older people or incompetent patients). It is not known to what extent refused requests for euthanasia result in patients ending their own life.

Since 2002, the Netherlands has been one of the few countries where euthanasia and physician-assisted suicide are, under strict conditions, regulated by law. Comparable laws exist in Belgium and Luxembourg; Oregon, Montana, Washington (USA) and Switzerland have legally regulated assistance in suicide.(7,8) In the Netherlands, euthanasia is defined as the administering of lethal drugs by a physician with the explicit intention to end the patient 's life on the patient's explicit request. In physician-assisted suicide the patient self-administers medication that was prescribed intentionally by a physician. In the Netherlands, the enactment of the euthanasia law was preceded by several decades of debate among medical practitioners, lawyers, ethicists, politicians and the general public in which a reporting procedure was developed.(7) This debate has been informed by nationwide studies on end-of-life decision-making, that were done in 1990, before the first reporting procedure, 1995, 2001, and 2005.(9-13) These studies have allowed monitoring of the practice of end-of-life decision-making in relation to development of the regulatory system. In 2005, three years after enactment of the euthanasia law, the euthanasia rate had decreased significantly, from 2.6% of all deaths in 2001, to 1.7% in 2005, which was a reversal of the trend from 1990 to 2001. Ending of life without an explicit request of the patient had decreased, albeit not significantly (0.7% in 2001 and 0.4% in 2005).(9) In 2010, eight years after enactment of the euthanasia law, we investigated how end-of-life decision making practices have further developed.

Methods

Study design

In 2010, we undertook a nationwide death-certificate study that was largely similar to earlier studies done in 1990, 1995, 2001 and 2005.(9-13) We drew a random sample from the central death registry of Statistics Netherlands, to which all deaths and causes are reported. The period studied was Aug 1, through Nov 1, in all studied years. All deaths that occurred in that period were assigned to one of five strata. When the cause of death clearly precluded end-of-life decision-making (e.g. instant death in a traffic accident), cases were assigned to stratum one. These cases were retained in the sample, but no questionnaires were sent out to the physician. On the basis of cause of death, cases were assigned to one of the other strata looking at the likelihood that an end-of-life decision had preceded death: when this decision was unlikely (eg, acute myocardial infarction or aneurysm) cause of death was allocated to stratum two, when this decision was possible (eg, heart failure or Parkinson's disease) to stratum three, and when this decision was more probable (eg, cancer) to stratum four. Cases were assigned to stratum five when the physician had noted on the death certificate that they had actively ended the life of the patient. The final sampling contained 50% of the cases of stratum five, 25% of the cases in stratum four, 13% of those in stratum three, 8.3% of those in stratum one and two. To ensure that children younger than 17 years of age and non-western immigrants, two small groups in death statistics, were represented well in the sample all deaths in which an end-of-life decision could not be precluded in these groups were sampled. All attending physicians of the sampled cases in strata two to five received a questionnaire. The data collection procedure precluded identification of physician and patient. The Ministry of Justice gave a guarantee that no physician could be prosecuted based on information given to the researchers. According to Dutch policy, the study did not require review by an ethics committee.

Questionnaire

The questionnaire focused on end-of-life decision making that might have preceded the death of the patient involved. The four key questions addressed whether the following factors (1) whether the respondent had withheld or withdrawn medical treatment while taking into account the possible hastening of death; (2) whether the respondent had intensified measures to alleviate pain or other symptoms while taking into account or partly intending the possible hastening of death; (3)) whether the respondent had withheld or withdrawn medical treatment with the explicit intention of hastening death; or (4) whether the respondent had administered, supplied, or prescribed drugs with the explicit intention of hastening death, resulting in the patient's death. These questions were validated in the 1990 and 1995 study, and were kept identical in all years studied. If more than one of the key questions was answered affirmatively, the act that involved the most explicit intention was used to classify the case. If the intention was similar, the administration of drugs prevailed over the withholding or withdrawing of treatment. If key question four was answered affirmatively and if the act was done in response to an explicit request by the patient, the act was classified as euthanasia or assisted suicide (depending on whether or not patients had taken the drugs themselves). If question four was answered affirmatively and the act was not done in responds to and explicit request by the patient, the act was classified as ending of life without explicit request.

Details about the decision-making process, the type of drugs that had been used, and the degree to which death had been hastened as estimated by the physician, were asked for the most important end-of-life decision, if any. Physicians were further asked to choose the term that they thought best described their end-of-life decision: 'forgoing treatment', 'alleviation of symptoms', 'palliative or terminal sedation', 'ending of life', 'assisted suicide', or 'euthanasia'. Finally, we asked whether the patient had been 'deeply and continuously sedated until death', whether the patient had made a request for euthanasia or physician-assisted suicide that was not granted, and whether patients had purposely ended their life by stopping eating and drinking.

Statistical analyses

All cases were weighted to adjust for the stratification procedure and for differences in response rates in relation to the age, sex, marital status, region of residence, and cause and place of death of the patients. The results were then extrapolated to 2010, to reflect all deaths in 2010 in the Netherlands (n=136 058). This weighting procedure was done in all years studied (1990, 1995, 2001, 2005 and 2010). As a result of this weighing procedure the percentages presented cannot be derived from the absolute unweighted numbers presented. 95% CIs were calculated. This procedure took into account the weighting by standardizing the weighting factors to the actual number of cases.

Role of funding source

The sponsor of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Results

Of the 8496 questionnaires that were mailed, 6263 were returned and eligible for analysis (response rate 74%). Response rates in the different strata ranged between 64% and 84%, with response being higher in strata in which the likelihood of an end-of-life decision was higher. Response rates in 1990, 1995, 2001, and 2005 were comparable (range 74% to 78%). The frequency of euthanasia increased between 2005 and 2010 (Table 1).

The frequency of physician-assisted suicide remained low over the years. The figure shows that the increase in the number of instances of euthanasia is related to both an increase in the number of explicit requests for euthanasia (from 4.8% [95% CI 4.4–5.2; 503 of 9965] of all deaths surveyed in 2005 to 6.7% [6.1–7.3; 766 of 6861] in 2010) and the proportion of requests that were granted (from 37% [252 of 503] to 45% [496 of 766] of requests).

The frequency of ending of life without an explicit patient request decreased over the years (from 0.8% [95% CI 0.6–1.1; 45 of 5197] of all deaths in 1990 to 0.2% [0.1–0.3%; 13 of 6861] in 2010). While the frequency of forgoing of life-prolonging treatment was relatively stable over the years, the frequency of intensified alleviation of symptoms increased, especially between 2005 and 2010. The percentage of all cases in which physicians intensified alleviation of symptoms, rather than only cases in which that action was most important, was 30% (29–31; 1832 of 5617) in 2005 and 45% (44–46; 2777 of 6861) in 2010. For forgoing treatment, the percentage of all cases in which treatment was forgone, thus also when this factor was not the most important, was 28% (95% CI 27–29; 1434 of 5617) in 2005 and 37% (36–39; 2103 of 6861) in 2010 (data not shown).

We also saw an increase of continuous deep sedation until death. A small proportion of patients in 2010 had intentionally hastened death by stopping eating and drinking (Table 1). Further analysis showed that in 0.2% (seven of 6861) of all deaths patients had intentionally stopped eating and drinking after an ungranted euthanasia request. Another 0.04% (13 of 6861) had committed suicide with drugs or another method after an ungranted euthanasia request. Thus, in 7% (20 of 270) of deaths in which the patient had made a ungranted euthanasia request the patient hastened death him or herself (data not shown).

Euthanasia and physician-assisted suicide most often concern younger people, cancer patients, and patients attended by general practitioners (Table 2). The decreased frequency of ending of life without explicit patient request is most pronounced in people younger than 65 years of age, where it decreased between 2001 and 2010, and among clinical specialists (Table 2). For intensified alleviation of symptoms the increase was consistently seen in all patient groups.

The most important reasons for the physician to grant the euthanasia requests that were mentioned most often in 2010 were the wish of the patient (85% [420 of 496]; 82% [219 of 262] in 2005), no prospect of improvement (82% [405 of 496]; 85% [223 of 262] in 2005), no more options for treatment (73% [370 of 496]; not asked in 2005), and loss of dignity (61% [311 of 496]; 60% [164 of 262] in 2005). Between 2005 and 2010, no clear differences were seen in the percentage of cases in which physician discussed end-of-life decisions with the patient, relatives, and other physicians. Both in 2005 and 2010, most cases of euthanasia and physician-assisted suicide were undertaken with neuromuscular relaxants and barbiturates. A non-significant decrease occurred in use of these drugs for ending of life without explicit request (from 29.4% [95% CI 14.9–49.4; seven of 24] to 1.6% [0.1–31.0; one of 13]). Intensified alleviation of symptoms was more commonly done with a combination of benzodiazepines and opioids in 2010 than in 2005 (Table 3). No clear differences were seen between the years in the estimated degree to which end-of-life decisions had shortened life. In 2010, euthanasia and physician-assisted suicide were estimated to have shortened the patient's life by a week or more in 58% (322 of 496) of cases, compared with 9% (one of 13) for ending of life without explicit request and 3% (61 of 2202) for intensified alleviation of symptoms. In over half of all cases of intensified alleviation of symptoms, the physician estimated that life had not been shortened; this is a small increase compared with 2005 (Table 3).

Finally, in 2010, of all physicians who had indicated in the questionnaire to have made an end-of-life decision that was classified as euthanasia or physician-assisted suicide, most classed "euthanasia", "assisted suicide", or "ending of life" the most appropriate term for their act, followed by "palliative or terminal sedation"; these classifications are comparable with 2005. In 2010, ending of life without explicit patient request was never labeled as "ending of life" (in 2005 about a fifth of cases were classed as "ending of life"); it was mostly labeled as "palliative or terminal sedation" or "alleviation of symptoms" (Table 3).

The absolute number of cases of euthanasia or physician-assisted suicide in 2010 was about 4050. In 2010, 3136 (77%) cases of euthanasia or physician-assisted suicide were reported to euthanasia review committees in the Netherlands.(14) In our questionnaire we also asked whether physicians had reported their act to a euthanasia review committee. With these data a similar reporting rate was calculated (Table 4). The reporting rate in 2010 is comparable with the reporting rate of 2005 (80%; 1933 of 2425), and higher than the reporting rate before enactment of the law (18% [486 of 2700] in 1990; 41% [1466 of 3600] in 1995, and 54% [2054 of 3800] in 2001). In the unreported cases the drugs used were hardly ever neuromuscular relaxants or barbiturates and the most appropriate term according to the physician was never "euthanasia" or "assisted suicide" (Table 4). Furthermore, in cases in which the physician had reported to a euthanasia review committee the estimated shortening of life was more often a week or more than in unreported cases (Table 4). Finally general practitioners were more inclined to report whereas clinical specialists were less inclined to report.

Table 1: Frequency of euthanasia, assisted suicide and other end-of-life practices in The Netherlands in 1990, 1995, 2001, 2005 and 2010

	1990	1995	2001	2005	2010
Number of deaths in the Netherlands	128 824	135 675	140 377	136 402	136 056
Number of studied cases	5197	5146	5617	9965	6861
Most important end-of-life decision					
Euthanasia	141 (1.7% [1.4–2.1])	257 (2.4% [2.1–2.6])	310 (2.6% [2.3–2.8])	294 (1.7% [1.5–1.8])	475 (2.8% [2.5–3.2])
Assisted suicide	18 (0.2% [0.1–0.3])	25 (0.2% [0.1–0.3])	25 (0.2% [0.1–0.3])	17 (0.1% [<0.1–0.1])	21 (0.1% [0.1–0.2])
Ending of life without explicit patient request	45 (0.8% [0.6–1.1])	64 (0.7% [0.5–0.9])	42 (0.7% [0.5–0.9])	24 (0.4% [0.2–0.6])	13 (0.2% [0.1–0.3])
Intensified alleviation of symptoms	1166 (18.8% [17.9–19.9])	1161 (19.1% [18.1–20.1])	1312 (20.1% [19.1–21.1])	1478 (24.7% [23.5–26.0])	2202 (36.4% [35.2–37.6])
Forgoing of life-prolonging treatment	991 (17.9% [17.0–18.9])	1097 (20.2% [19.1-21.3])	1210 (20.2% [19.1–21.3])	767 (15.6% [15.0–16.2])	974 (18.2% [17.3–19.1])
Total	2361 (39.4% [38.1–40.7])	2604 (42.6% [41.3–43.9])	2899 (43.8% [42.6–45.0])	2570 (42.5% [41.1-43.9])	3685 (57.8% [56.7–59.0])
Continuous deep sedation†*	NA	NA	..	521 (8.2% [7.8–8.6])	789 (12.3% [11.6–13.1])
Patient deciding to end life by stopping eating and drinking	NA	NA	NA	NA	18 (0.4% [0.3–0.6])

Data are absolute number or number of patients (weighted % [95% CI]). All percentages are weighted for sampling fractions, non-response, and random sampling deviations, to make them representative for all deaths in the year studied. Therefore, the percentages presented cannot be derived from the unweighted absolute numbers presented. NA=not available. *Continuous deep sedation might have been provided in conjunction with practices that possibly hastened death. †In 2001, continuous deep sedation was only studied when it occurred in conjunction with an end-of-life decision; the frequency was 5.6%; corresponding numbers are 7.1% in 2005 and 11% in 2010.

Table 2: Frequencies of euthanasia or physician-assisted suicide, ending of life without explicit request, and intensified alleviation of symptoms in 2001, 2005 and 2010, according to patient characteristics

	All deaths in 2010 (%)	Euthanasia and physician-assisted Suicide			Ending of life without explicit Request			Intensified alleviation of symptoms		
		2001	2005	2010	2001	2005	2010	2001	2005	2010
Age (years)										
0-64 (n=2079)	19%	139 (5.0% [4.1-6.0])	131 (3.5% [2.7-4.4])	191 (5.6% [4.6-6.7])	11 (1.0% [0.7-1.5])	13 (1.0% [0.7-1.5])	4 (0.2% [0.1-0.5])	303 (18.9% [17.3-20.7])	384 (21.4% [19.7-23.2])	533 (30.5% [28.5-32.5])
65-79 (n=2156)	31%	134 (3.3% [2.6-4.1])	126 (2.1% [1.5-2.8])	191 (4.0% [3.2-4.9])	11 (0.4% [0.2-0.8])	5 (0.3% [0.1-0.6])	4 (0.3% [0.1-0.6])	456 (20.8% [19.1-23.5])	536 (25.4% [23.4-26.7])	721 (35.3% [33.3-37.3])
≥80 (n=2626)	51%	58 (1.4% [1.0-1.9])	54 (0.8% [0.5-1.2])	114 (1.4% [1.0-1.9])	20 (0.7% [0.4-1.1])	6 (0.2% [0.1-0.4])	5 (0.2% [0.1-0.4])	553 (20.2% [18.6-21.7])	558 (25.6% [24.2-27.6])	948 (39.2% [37.1-40.8])
Sex										
Male (n=3538)	49%	175 (3.1% [2.6-3.7])	181 (2.0% [1.6-2.5])	281 (3.5% [2.9-4.2])	19 (0.7% [0.5-1.0])	11 (0.4% [0.2-0.7])	7 (0.2% [0.1-0.4])	591 (19.1% [17.7-20.3])	731 (23.7% [22.4-25.2])	1101 (34.5% [33.4-36.5])
Female (n=3278)	52%	156 (2.5% [2.0-3.1])	130 (1.5% [1.1-2.0])	215 (2.5% [1.9-3.0])	23 (0.7% [0.4-1.0])	13 (0.4% [0.2-0.7])	6 (0.2% [0.1-0.4])	721 (21.1% [19.6–22.4])	747 (25.7% [24.5–27.5])	1101 (38.2% [36.4–39.6])
Cause of death										
Cancer (n=3055)	31%	280 (7.4% [6.5-8.4])	269 (5.1% [4.4-6.0])	415 (7.6% [6.7-8.6])	24 (1.0% [0.7-1.4])	9 (0.3% [0.1-0.6])	6 (0.2% [0.1-0.4])	709 (33.4% [31.2–34.6])	989 (37.1% [35.1–38.7])	1369 (47.7% [46.2–49.8])
Cardiovascular disease (n=931)	22%	6 (0.4% [0.1-1.0])	7 (0.3% [0.1-0.9])	15 (0.5% [0.2-1.3])	4 (0.6% [0.2-1.4])	2 (0.2% [0.1-0.8])	0	128 (11.1% [9.0–13.0])	175 (14.3% [11.8–16.3])	193 (21.5% [18.7–24.5])
Other or unknown (n=2875)	47%	45 (1.2% [0.8-1.7])	35 (0.4% [0.2-0.7])	66 (1.1% [0.8-1.6])	14 (0.5% [0.3-0.8])	13 (0.6% [0.3-0.9])	7 (0.3% [0.1-0.6])	475 (17.1% [15.6–18.4])	314 (24.1% [22.4–25.6])	640 (36.0% [34.2–37.8])

Table 2 (continued): Frequencies of euthanasia or physician-assisted suicide, ending of life without explicit request, and intensified alleviation of symptoms in 2001, 2005 and 2010, according to patient characteristics

	All deaths in 2010 (%)	**Euthanasia and physician-assisted Suicide**			**Ending of life without explicit Request**			**Intensified alleviation of symptoms**		
		2001	**2005**	**2010**	**2001**	**2005**	**2010**	**2001**	**2005**	**2010**
Type of physician*										
General practitioner (n=3424)	45%	274 (5.8% [5.1-6.7])	272 (3.7% [3.1-4.4])	456 (5.8% [5.1-6.7])	20 (0.6% [0.4-0.9])	6 (0.2% [0.1-0.4])	5 (0.2% [0.1-0.4])	609 (20.9% [19.6–22.4])	686 (23.9% [22.5–25.3])	1152 (34.3% [32.4–35.6])
Clinical specialist (n=1248)	26%	48 (1.8% [1.1-2.7])	22 (0.5% [0.2-1.0])	16 (0.9% [0.4-1.6])	18 (1.2% [0.7-2.0])	7 (0.7% [0.3-1.4])	2 (0.4% [0.1-0.9])	300 (18.2% [15.9–20.2])	352 (22.7% [20.5–25.1])	546 (32.1% [29.4–34.6])
Elderly care physician (n=1588)	29%	9 (0.4% [0.1-0.8])	12 (0.2% [0.1-0.6])	29 (0.4% [0.1-0.8])	4 (0.4% [0.1-0.8])	4 (0.3% [0.1-0.7])	6 (0.2% [0.1-0.6])	403 (31.7% [29.7–34.3])	410 (35.7% [33.6–38.3])	504 (45.8% [43.5–48.4])
Total (n=6861)	100%	331 (2.8% [2.4-3.2])	311 (1.8% [1.5-2.1])	496 (3.0% [2.5-3.3])	42 (0.7% [0.5-0.9])	24 (0.4% [0.2-0.6])	13 (0.2% [0.1-0.3])	1312 (20.1% [19.1-21.1])	1478(24.7% [23.5–26.0)	2202 (36.4% [35.2–37.6])

Data are percentage or absolute number of patients (weighted % [95% CI]). Percentages are weighted for sampling fractions, non-response, and random sampling deviations, to make them representative of all deaths in the year studied. Therefore, the percentages presented cannot be derived from the unweighted absolute numbers presented. *Missing observations for 2005: five for euthanasia and physician-assisted suicide, six for ending of life without explicit request, and 30 for intensified alleviation of symptoms.

Table 3: Characteristics of euthanasia or physician-assisted suicide, ending of life without explicit request, and intensified alleviation of symptoms, in 2005 and 2010

	Euthanasia and physician-assisted suicide		Ending of life without explicit request		Intensified alleviation of symptoms	
	2005 (n=262)	**2010 (n=496)**	**2005 (n=24)**	**2010 (n=13)**	**2005 (n=1478)**	**2010 (n=2202)**
Discussion						
Discussion with or previous wish of patient	262 (100.0%)	496 (100.0%)	10 (60.0% [36.6–77.9])	6 (59.1% [31.6–86.1])	554 (35.3% [32.5–37.4])	760 (32.9% [31.1–35.0])
Discussion with relative(s)	200 (75.5% [70.0–80.4])	346 (70.5% [67.0–75.0])	13 (80.9% [57.8–92.9])	7 (72.2% [38.6–90.9])	724 (54.0% [51.5–56.5])	962 (48.6% [46.9–51.1])
Discussion with other physician(s)	230 (87.7% [84.3–92.1])	459 (93.8% [91.5–95.9])	15 (65.3% [44.7–84.4])	5 (53.4% [25.1–80.8])	411 (29.5% [27.6–32.3])	596 (27.9% [26.1–29.9])
No discussion with any of the above	0	0	4 (19.1% [7.1–42.2])	5 (24.9% [5.0–53.8])	613 (38.2% [35.5–40.5])	994 (41.2% [39.0–43.1])
Drugs*						
Neuromuscular relaxants†	197 (67.0% [61.5–72.9])	392 (72.2% [68.0–75.9])	5 (23.4% [9.7–46.7])	1 (1.6% [0.1–36.0])	..	..
Barbiturates†	10 (8.5% [6.0–13.3])	37 (7.9% [5.8–10.8])	2 (6.0% [0.2–21.5])	0	..	..
Benzodiazepines and opioids	9 (6.7% [4.1–10.6])	28 (13.3% [10.0–15.9])	5 (22.4% [7.1–42.2])	4 (26.1% [5.2–54.1])	384 (23.7% [21.8–26.6])	853 (37.1% [35.0–39.0])
Benzodiazepines	7 (7.0% [4.1–10.6])	7 (3.0% [10.0–15.9])	1 (3.3% [0.1–21.1])	1 (9.0% [0.1–36.3])	71 (3.5% [3.1–5.1])	119 (4.8% [4.1–6.0])
Opioids	13 (10.5% [7.3–14.9])	5 (3.1% [1.7–4.9])	7 (40.2% [22.1–63.4])	7 (63.3% [32.2–86.4])	947 (69.4% [66.7–71.4])	1134 (56.4% [53.9–58.1])

Table 3 (continued): Characteristics of euthanasia or physician-assisted suicide, ending of life without explicit request, and intensified alleviation of symptoms, in 2005 and 2010

	Euthanasia and physician-assisted suicide		Ending of life without explicit request		Intensified alleviation of symptoms	
	2005 (n=262)	**2010 (n=496)**	**2005 (n=24)**	**2010 (n=13)**	**2005 (n=1478)**	**2010 (n=2202)**
Other	1 (0.3%)	2 (0.5% [0.3–2.3])	3 (4.7% [0.2–21.3])	0	58 (3.4% [2.2–4.0])	37 (1.7% [1.2–2.3])
Shortening of life						
Probably no life shortening	2 (0.7% [0.2–3.3])	1 (0.4%)	3 (17.2% [4.7–37.4])	1 (9.4% [0.1–36.3])	778 (54.2% [51.5–56.5])	1275 (58.6% [56.9–61.0])
Less than a week	101 (44.1% [37.9–49.9])	166 (40.3% [35.6–44.2])	14 (68.3% [44.7–84.4])	10 (76.1% [46.2–95.0])	397 (26.8% [24.7–29.3])	587 (26.9% [25.2–28.9])
A week or more	153 (53.9% [47.8–59.9])	322 (58.0% [53.7–62.4])	6 (11.6% [2.7–32.3])	1 (9.1% [0.1–36.3])	47 (3.4% [2.2–4.0])	61 (3.1% [2.3–3.8])
Unknown	6 (1.3% [0.2–0.3])	7 (1.3% [0.3–2.3])	1 (2.9% [0.1–21])	1 (5.4% [0.1–36.3])	256 (15.6% [14.1–17.8])	279 (11.4% [9.7–12.3])
Most appropriate term for decision according to physician						
Euthanasia or assisted suicide	225 (82.8% [78.3–87.4])	412 (76.7% [73.3–80.7])	0	0	0	1 (<0.1%)
Ending of life	5 (0.5% [0.2–3.3])	9 (2.0% [1.0–3.7])	4 (17.2% [4.7–37.4])	0	0	1 (<0.1%)
Alleviation of symptoms	7 (3.6% [1.9–6.9])	2 (1.5% [1.0–3.7])	8 (33.3% [15.6–55.3])	4 (40.6% [13.9–68.4])	849 (57.5% [54.4–59.5])	1201 (57.5% [55.9–60.1])
Non-treatment decision	1 (0.2%)	0	1 (3.9% [0.1–21])	1 (1.7% [0.0–36])	79 (5.5% [4.0–6.2])	625 (8.3% [6.9–9.2])

Table 3 (continued): Characteristics of euthanasia or physician-assisted suicide, ending of life without explicit request, and intensified alleviation of symptoms, in 2005 and 2010

	Euthanasia and physician-assisted suicide		Ending of life without explicit request		Intensified alleviation of symptoms	
	2005 (n=262)	2010 (n=496)	2005 (n=24)	2010 (n=13)	2005 (n=1478)	2010 (n=2202)
Palliative or terminal sedation	22 (12.2% [7.9–15.7])	44 (18.1% [14.6–21.3])	10 (41.8% [22.1–63.4])	7 (52.2% [25.1–80.8])	281 (19.2% [17.0–21.0])	486 (20.3% [18.3–21.7])
Unknown	2 (0.7% [0.1–2.7])	8 (1.7% [1.0–3.7])	1 (3.8% [0.1–21.1])	1 (5.5% [0.1–36.3])	269 (17.8% [16.0–20.0])	355 (13.9% [12.5–15.4])

Data are absolute number of patients (weighted % [95% CI]). Percentages are weighted for sampling fractions, non-response and random sampling deviations, to make them representative for all deaths in the year studied. Therefore, the percentages presented cannot be derived from the unweighted absolute numbers presented. *Drugs could have been neuromuscular relaxants, in any combination; barbiturates, alone or in combination with other drugs except neuromuscular relaxants; the combination of benzodiazepines and opioids possibly in combination with other drugs except neuromuscular relaxants or barbiturates; benzodiazepines alone or in combination with other drugs except neuromuscular relaxants, barbiturates, and opioids; or other drugs than the ones mentioned above. †Not asked separately for intensified alleviation of symptoms.

Table 4: Characteristics of reported and unreported cases of euthanasia and physician-assisted suicide

	Not reported (n=45)	Reported (n=443)	Total (n=496)*
Age (years)			
0-64	14 (20.5% [9.5–34.6])	174 (38.1% [33.4–42.4])	191 (34.8% [30.9–39.3])
65-79	18 (47.3% [31.7–62.1])	170 (39.4% [34.5–43.6])	191 (40.7% [36.6–45.3])
≥80	13 (32.2% [18.2–46.6])	99 (22.5% [18.0–25.7])	114 (24.5% [21.2–28.8])
Sex			
Male	24 (53.7% [37.9–68.3])	254 (58.1% [53.4–62.6])	281 (57.2% [52.7–61.4])
Female	21 (46.3% [31.7–62.1])	189 (41.9% [37.4–46.6])	215 (42.8% [38.6–47.3])
Cause of death			
Cancer	36 (63.4% [46.5–76.2])	371 (83.1% [79.6–86.6])	415 (79.1% [75.4–82.6])
Cardiovascular disease	2 (9.8% [3.7–24.1])	13 (2.5% [1.6–5.0])	15 (4.0% [2.5–6.2])
Other/unknown	7 (26.8% [14.6–41.9])	59 (14.4% [10.8–17.2])	66 (16.9% [13.6–20.2])
Type of physician			
General practitioner	36 (71.4% [55.7–83.6])	408 (92.5% [90.2–95.2])	269 (88.1% [85.0–90.8])
Clinical specialist	2 (23.8% [12.9–39.5])	14 (4.4% [2.4–6.3])	7 (8.4% [5.8–10.8])
Elderly care physicians	7 (4.8% [0.5–15.2])	21 (3.1% [1.6–5.0])	35 (3.5% [2.5–6.2])
Drugs			
Neuromuscular relaxants	1 (<0.1%)	386 (90.2% [86.9–92.7])	392 (72.2% [68.0–75.9])
Barbiturates	1 (<0.1%)	36 (9.8% [7.3–13.1])	37 (7.9% [5.8–10.8])
Benzodiazapines and opioids	28 (66.7% [51.0–80.0])	0	28 (13.3% [10.0–15.9])
Benzodiazepines	7 (15.4% [6.5–29.4])	0	7 (3.0% [1.7–4.9])
Opioids	5 (15.4% [6.5–29.4])	0	5 (3.1% [1.7–4.9])
Other	1 (2.5% [0.1–11.8])	1 (<0.1%)	2 (0.5% [0.3–2.3])
Shortening of life			
Probably no life shortening	1 (2.6% [0.1–11.8])	0	1 (<0.4%)
Less than a week	39 (87.0% [73.2–94.9])	126 (28.2% [23.8–32.2])	166 (40.3% [35.6–44.2])
A week or more	5 (10.4% [3.7–24.1])	315 (71.3% [66.9–75.3])	322 (58.0% [53.7–62.4])
Unknown	0	2 (0.6% [0.3–2.3])	7 (1.3% [0.3–2.3])

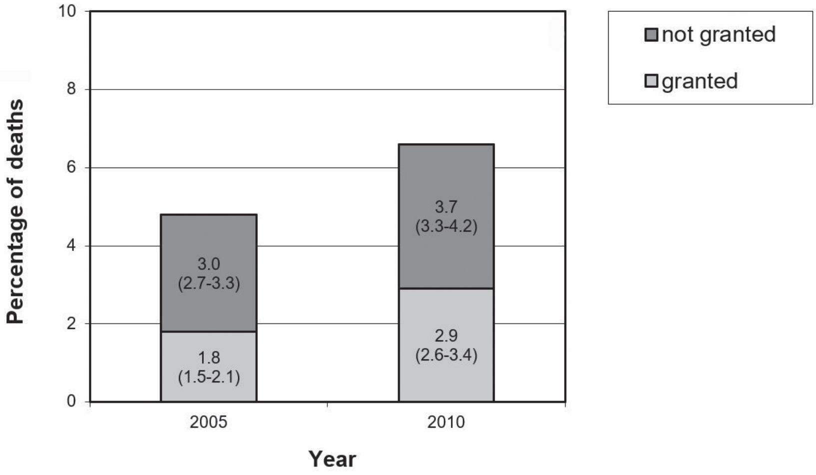
Table 4 (continued): Characteristics of reported and unreported cases of euthanasia and physician-assisted suicide

	Not reported (n=45)	Reported (n=443)	Total (n=496)*
Most appropriate term for the act according to physician			
Euthanasia or assisted suicide	0	432 (97.4% [95.0–98.4])	412 (76.7% [73.3–80.7])
Ending of life	1 (2.5% [0.1–11.8])	8 (1.6% [0.9–3.8])	9 (2.0% [1.0–3.7])
Alleviation of symptoms	2 (7.5% [2.5–21])	0	2 (1.5% [1.0–3.7])
Palliative or terminal sedation	4 (90.0% [2.5–21.2])	2 (0.7% [0.3–2.3])	44 (18.1% [14.6–21.3])

Data are absolute number of patients (weighted % [95% CI]). All percentages are weighted for sampling fractions, non-response, and random sampling deviations, to make them representative of all deaths in the Netherlands in 2010.

Therefore, the percentages presented cannot be derived from the unweighted absolute numbers presented. *For eight cases, it was not known whether the physician had reported the case to a euthanasia review committee.

Figure 1: Weighted percentage (95% CI) of all deaths preceded by a granted or ungranted request for euthanasia a or physician-assisted suicide



A request can be ungranted for different reasons, among which a refusal of the physician, or the patient dying before the physician could decide on granting the request. There were 9965 deaths in 2005 and 6861 deaths in 2010. Absolute unweighted numbers: 252 granted requests and 251 ungranted for euthanasia in 2005; and 496 granted requests and 270 ungranted requests in 2010.

Discussion

After the modest decrease in euthanasia frequency three years after enactment of the euthanasia law, we saw an increase eight years after the enactment. A rise in the number of patients requesting euthanasia explains this increase partly. While more than half of these requests were not granted, physicians granted request more often in 2010 than in 2005. As differences occurred in patient characteristics of cases of euthanasia and physician-assisted suicide, the increase seems not due to expansion to other patient groups.

Euthanasia is still mostly undertaken in younger people, cancer patients, and in general practice rather than in hospitals or nursing homes. As the rate of euthanasia and physician-assisted suicide in 2010 was comparable to the rate before enactment of the law in 2001, some physicians might have been unsure about how the law would work in practice, in 2005, shortly after the enactment of the law, making them more reluctant to undertake euthanasia. In Belgium, the euthanasia rate decreased from 1.1% in 1998 to 0.3% in 2001, shortly before enactment of the law in 2002, increasing again to 1.9% in 2007.(15) Although in Belgium the increase occurred just before the enactment of the law, this might represent a similar phenomenon as in the Netherlands because in Belgium the euthanasia law was heavily debated before its enactment.(16)

After publication of the Dutch 1990 study (13), the subject that raised the most international debate was the number of cases of ending of life without an explicit patient request (panel).(18,19) The frequency of this practice has been decreasing since. One reason for this decrease might be the increased attention for palliative care over the last decade.(20,21) Additionally, this decrease might be related to the regulation of euthanasia and physician-assisted suicide, through enabling patients and physicians to openly discuss end-of -life preferences. In Belgium, where a euthanasia law was enacted in 2002, the rate of ending of life without request was higher in 1998 (3.2%) than in 2001 (1.5%) and 2007 (1.8%).(15) In the UK the rate ending life without request was stable between 2004 and 2008 (0.3%).(22) While there is debate in the UK about regulation of assisted dying, no law exists on euthanasia or physician-assisted suicide in the UK. Not withstanding the decrease of ending of life without explicit requests, information on characteristics of these cases is important to assess this practice. Although the absolute numbers are small, in half of these cases the decision has been discussed with the patient and in a quarter of cases the physician did not discuss the decision with either patient, relative, or other physicians.

The frequency of intensified alleviation of symptoms has risen, especially between 2005 and 2010. This finding is unexpected because evidence shows that the life-shortening effects of opioids are often overestimated.(23-25) Yet, in over half of the cases in which symptoms were alleviated while taking into account a possible life-shortening effect, the physician thought that life had actually not been shortened. Knowledge about the limited life-shortening potential of opioids thus might have taken away reluctance in physicians and patients to use opioids. This effect is probably related to increased attention for palliative care in the Netherlands, which could also explain the rising use of continuous deep sedation until death.(20-21) This finding is in line with results s of a study in Dutch nursing homes showing an increase in the use of pain relief and no change in treatment with antibiotics of dementia patients with pneumonia over a decade. (26) In Belgium, an increase in intensified alleviation of pain and symptoms and in continuous deep sedation also coincided with increased attention for palliative care.(15) In the UK, a decrease in the use of intensified alleviation of symptoms was noted, from 30% in 2004 to 22% in 2008. However, whether these rates are comparable is debatable because in 2004 wording in the questionnaire was similar to the wording in our studies (taking into account possible life-shortening effect), whereas in 2008 the wording was different (knowledge of probable or certain hastening of life).(20)

We noted that in 2010, according to their physician, in 0.4% of all deaths the patient intentionally had stopped eating and drinking. This is substantially lower than the rate recorded in a proxy-report in a Dutch population-based survey in 2009.(27) Physicians are not always aware of patients intentionally stopping eating and drinking. The survey showed that in 72% of cases the person stopping eating and drinking had a disease diagnosis. However, a sample of deceased persons might yield more accurate estimates of end-of-life practices than a population-based sample of proxies. We noted that in almost half of patients who intentionally stopped eating and drinking, they had made a euthanasia request that was not granted, which is a similar percentage as reported in the proxy survey. While this proportion is substantial, it is a minority of all deceased patients whose request did not result in euthanasia. An even smaller group committed suicide after their euthanasia request was not granted. We are not aware of studies of patients intentionally ending their life in the course of a serious illness in other countries. Whether the legal option of euthanasia or physician-assisted suicide influences these rates would be interesting to know.

Eight years after enactment of the euthanasia law the percentage of cases that were reported to the reviews committees, which is a legal obligation, stabilized. In unreported cases virtually all physicians labeled their decision themselves as 'palliative or terminal sedation' or as 'alleviation of symptoms', and none of them used neuromuscular relaxants or barbiturates. By contrast, in reported cases virtually all physicians labeled their act as 'euthanasia' or 'assisted suicide', and all used neuromuscular relaxants or barbiturates, the drugs advised for undertaking euthanasia or physician-assisted suicide by the Royal Dutch Association for Pharmacy and by the Euthanasia Review Committees. These characteristics of unreported cases have led some to argue that cases of euthanasia in which opioids are used should not be included in the euthanasia rate.(28) Excluding unreported cases would make for a reporting rate of about 100% both in 2005 and 2010. However, use of opioids was only classified as euthanasia when physicians affirmed that death was caused by administering this drug with the intention to end life. Hastening of death by administration of opioids in these cases cannot be ruled out. Obviously, the classification scheme used in our studies is more likely to result in an overestimation than in an underestimation of the euthanasia frequency. In any case, our finding that about 100% of the cases in which the advised drugs were used were reported, suggests that non-reporting by physicians is not related to unwillingness to report cases of euthanasia. This finding seems more related to lack of clarity about or discrepancy between effects of drugs and intention with regard to hastening death. Further education seems the most appropriate way to further increase reporting rate.

Together with the high response rates and the availability of data for over two decades, an important strength of the study is the substantial sample of deaths that is representative for all deaths in all settings nationwide. A limitation is that information is derived from physicians, making us rely on the physicians' assessment of the situation. While this approach is the best source for information on the physicians' experiences, such as the physicians' intention or the most appropriate term for the decision according to the physician, it can be more difficult for physicians to assess the life-shortening effect of drugs. Additionally, physicians might give socially desirable answers. However, we noted a similar reporting rate when com paring reporting based on information given by our respondents with the actual number of cases of euthanasia and physician-assisted suicide reported to Euthanasia Review Committees in 2010.(14) Finally, our study does not enable the assessment of quality of care or decision making on the patient level. For instance, to assess whether symptom control was sufficient is not possible. Our study's strength lies in providing populationlevel information relevant to health policy.

In conclusion, eight years after the enactment of the Dutch euthanasia law, the incidence of euthanasia and physician-assisted suicide is comparable with that in the period before the law. The reporting rate seems to have stabilized at about eight out of ten cases. Euthanasia and physician-assisted suicide did not shift to different patient groups and the frequency of ending of life without explicit request continued to fall. Although translating these results to other countries is not straightforward, they can inform the debate on legalization of euthanasia or physician-assisted suicide in other countries.

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CHAPTER 9

Involvement of supportive care professionals in patient care in the last month of life

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Abstract

Background
In the last month of life, many patients suffer from multiple symptoms and problems. Professional supportive care involvement may help to alleviate patients' suffering and provide them with an optimal last phase of life.

Purpose
We investigated how often palliative care consultants, pain specialists, psychological experts, and spiritual caregivers are involved in caring for patients in the last month of life, and which factors are associated with their involvement.

Methods
Questionnaires were mailed to physicians who had attended the death of a patient from a stratified sample of 8496 deaths that had occurred in 2010 in the Netherlands. The response rate was 74% (n=6263).

Results
A palliative care team or consultant had been involved in the last month of life in 12% of all patients for whom death was expected; this percentage was 3% for pain specialists, 6% for psychologists or psychiatrists, and 13% for spiritual caregivers. Involvement of palliative care or pain specialists was most common in younger patients, in patients with cancer and in patients who died at home. Involvement of psychological or spiritual caregivers was most common in older patients, in females, in patients with dementia, and in patients who died in a nursing home. Involvement of supportive caregivers was also associated with the use of morphine and end-of-life decisions.

Conclusion
Supportive care professionals are involved in end-of-life care in about a quarter of all non-suddenly dying patients. Their involvement is related to the setting where patients die, to patient's characteristics and complex ethical decision-making.

Introduction

At the end of life, patients with cancer or other life-threatening diseases may develop a variety of symptoms and problems, either physical, psychological or spiritual, which can be distressing and detrimental to their quality of life.(1-5) In patients with incurable cancer, symptoms like fatigue, pain, lack of energy, weakness and appetite loss occur in more than 50% of the patients.(2) Patients with advanced chronic obstructive pulmonary disease and chronic heart failure reported multiple symptoms that are often undertreated (6) and inappropriate symptom treatment has been reported for patients with dementia.(7, 8)

Palliative and supportive care aim to relieve suffering and improve the quality of life for patients with advanced illnesses and their families. It is based on an interdisciplinary approach that can be offered simultaneously with disease-oriented treatment and involves attention to the emotional, spiritual, and practical needs and goals of patients, and of the people who are close to them.(9, 10) Although there is discussion about the terminology, there is considerable overlap between palliative and supportive care.(11) The phrase ‘palliative care’ is in principle used for patients with a limited life expectancy due to an incurable disease, whereas the phrase ‘supportive care’ can be used for all patients with chronic diseases. Both focus on symptom management, psychosocial care, communication, complex decision making, and transition of goals of care.(12) There is growing evidence that palliative care improves the quality of the last phase of life for patients and (13-17) and their relatives.(18, 19)

In a study by Murtagh et al. (2014), based on underlying and contributory causes of death, it was estimated that in high income countries between 69% and 82% of those who die need palliative care.(20)

In the Netherlands, palliative and supportive care are mainly provided by general health care professionals.(21) There is a strong emphasis on primary care which is professional health care as provided in the community, usually by a general practitioner (GP), home care nurses, and sometimes other health professionals; almost one third of all deaths in the Netherlands occur in the home setting.(22) Palliative care is not officially recognized as a medical specialty, but there are professionals who are trained in palliative care. It is acknowledged that in some cases, palliative care experts are needed to provide symptom relief, psychosocial support or support in end-of-life decision making. This awareness has resulted in a growing attention for palliative care and an increasing number of palliative care services such as hospices, palliative care units in nursing homes and palliative care consultation services, over the past years.(23) Since 1996, the Dutch Government developed a policy to support and enhance palliative care. At the moment, there are 25 palliative care consultation teams, covering all of the country.(24) These teams can be consulted by all professionals involved in palliative care, but in practice they are mainly consulted by general practitioners.(24) The aim of these teams is not to take over care, but to inform, support and advise the attending professional caregivers.(21) More recently, both hospitals and nursing homes are developing palliative care consultation services.(25) According to the WHO definition, all patients with a life-threatening illness could benefit from palliative care.(10) Until now, it is not known how often general caregivers involve professionals specialized in supportive or palliative care for patients who are in the last phase of life and which factors are associated with the involvement of these caregivers. We performed an observational study to answer the following research questions:

1. How often are palliative care consultants, pain specialists, psychologists, psychiatrists and spiritual caregivers involved in caring for patients in the last month of life?
2. Which characteristics of patients and the setting where they are being cared for are associated with the involvement of supportive care professionals?
3. Which end-of-life decisions are associated with the involvement of supportive care professionals?

Materials and Methods

Study design and data collection

In 2010 a cross-sectional study was performed. A stratified sample was drawn from the central death registry of Statistics Netherlands, which receives death certificates for all deaths in the Netherlands. When the cause of death was one in which it was clear that no physician's assistance in dying could have been provided (e.g. instant death in a traffic accident), cases were assigned to stratum one. On the basis of cause of death, cases were assigned to one of the other strata looking at the likelihood that an end-of-life decision had preceded death: when this decision was unlikely (e.g., acute myocardial infarction or aneurysm) cause of death was allocated to stratum two, when this decision was possible (e.g., heart failure or Parkinson's disease) to stratum three, and when this decision was more probable (e.g. cancer) to stratum four. Cases were assigned to stratum five when the physician had noted on the death certificate that they had actively ended the life of the patient. The final sampling contained 50% of the cases of stratum five, 25% of the cases in stratum four, 13% of those in stratum three, 8% of those in stratum one and two. All attending physicians of the sampled cases in strata two to five received a questionnaire.(26)

Population and setting

The sample was drawn from all deaths that had occurred between Augustus 1 and November 30 in 2010 (n=8496). A written questionnaire was mailed to the attending physician. Of the 8496 mailed questionnaires, 6263 were returned resulting in a response rate of 74%. Responding physicians represented all health care settings: general practitioners providing care for patients living at home and in care homes, elderly care physicians providing care in nursing homes and medical specialists providing care in hospitals.

Questionnaire

The attending physician was requested to complete the 4-page questionnaire, containing mainly multiple choice questions. The questionnaire focused on the characteristics of the end-of-life decision making that may have preceded the death of the patient involved. The wording of these questions was validated in previous studies that were performed in 1990 and 1995 and was kept identical in subsequent studies that were performed in 2001, 2005 and 2010. In 2010, questions on medical treatment and care in the last phase of life were added. These included the question "Which caregivers were involved in caring for the patient in the last month of life?" Respondents could choose from 5 options: a palliative care consultant or palliative care team, a pain specialist, a psychologist or psychiatrist, a spiritual caregiver (or chaplain), or another professional.

Statistical analysis

We analyzed data for patients whose death was reported to have occurred non-suddenly. Multivariable logistic regression analysis was performed with SPSS version 20 to identify factors associated with the involvement of different care professionals. In case of the question regarding the involvement of supportive care professionals, respondents sometimes mentioned 'other professionals' who could be recoded to one of the four professions of interest. In multivariable logistic regression models to assess factors associated with involvement of supportive caregivers, we combined the involvement of palliative care consultants, palliative care teams and pain specialists, because we assumed that these specialties mainly focus on physical causes of suffering. We also combined involvement of psychologists, psychiatrists and spiritual caregivers, assuming that these specialties mainly focus on non-physical causes of suffering. For both types of supportive caregivers, we assessed whether their involvement was associated with patient characteristics (age, gender, diagnosis), place of death, hospitalization during the last month of life, and the aim of care during the last phase of life (palliation or life prolongation). A second multivariable logistic regression analysis was performed to assess associations between the involvement of supportive caregivers and the use of morphine in the last 24 hours before death, the use of continuous deep sedation and different types of end-of-life decisions (forgoing life prolonging treatment, intensive forms of alleviation of symptoms and euthanasia).

Results

Involvement of supportive care professionals in the last month of life

Table 1 shows that in 27% of all cases of patients who had died a non-sudden death, one or more supportive caregivers had been involved in the care in the last month of life. Three percent of all non-sudden deaths had involved care of a pain specialist, in 12% a palliative care team or palliative care consultant had been involved, in 6% a psychiatrist or psychologist and in 13% a spiritual caregiver.

Table 1: Involvement of supportive care professionals in the last month of life

	Non-sudden deaths in the Netherlands in 2010 (N=4930)
	% (n)
Palliative care team / consultant	12 (785)
Pain Specialist	3 (246)
Psychologist / psychiatrist	6 (263)
Spiritual caregiver	13 (613)
Any supportive caregiver	27 (1540)

All percentages are weighted for sampling fractions, non-response, and random sampling deviations, to make them representative for all non-sudden deaths in the Netherlands in 2010.

In the multivariable logistic regression model, involvement of palliative care or pain specialists was most likely for patients aged 0-64 (26%, odds ratio(OR)=2.28, Confidence Interval (CI) 1.79-2.89) or 65-79 years (20%, OR=1.91, CI 1.55-2.36), for patients who were diagnosed with cancer (28%, OR=2.58, CI 2.03-3.28), for patients who were hospitalized in the last month of life (17%, OR=1.28 , CI 1.06-1.53) and for patients who died at home (20%, OR= 1.29 , CI 1.01-1.66) or in a nursing home (10%, OR=1.40 , CI 1.04-1.89). Palliative care and pain specialists were rarely consulted for patients diagnosed with dementia (4%, OR=0.39, CI 0.27-0.55). Palliative care and pain specialists were also more often consulted for patients for whom care had been aimed at palliation during the last weeks or months of life (21%, OR=3.98, CI 2.93-5.41) or days of life (14%, OR= 3.11, CI 2.26-4.27) (Table 2).

Table 2: Patient and care characteristics associated with involvement of palliative care and pain specialists in the last month of life

Palliative care and pain specialist involvement					
	n	**% (column)**	**% (row)**	**Univariate logistic regression OR (95% CI)**	**Multivariate logistic regression OR (95% CI)**
Overall	5062		14.0		
Age					
- 0-64	1312	16.0	26.3	*4.50 (3.66-5.54)*	*2.28 (1.79-2.89)*
- 64-79	1663	30.2	19.5	*3.06 (2.55-3.68)*	*1.91 (1.55-2.36)*
- > 80 (ref)	2087	53.8	7.3	1	
Sex					
- Female	2518	53.5	12.4	*0.76 (0.65-0.89)*	0.96 (0.81-1.15)
- Male (ref)	2544	46.5	15.7	1	1
Cause of Death					
- Cardiovascular disease	543	16.5	6.0	1.07 (0.78-1.48)	1.05 (0.75-1.49)
- Cancer	2925	37.2	27.9	*6.54 (5.37-7.95)*	*2.58 (2.03-3.28)*
- Other or unknown (ref)	1594	46.3	5.6	1	1
Dementia					
- Yes	739	23.0	4.0	*0.20 (0.15-0.27)*	*0.39 (0.27-0.55)*
- No (ref)	4104	77.0	17.2	1	1
Place of death					
- Home and residential home	2663	42.8	20.0	*2.53 (2.07-3.10)*	*1.29 (1.01-1.66)*
- Nursing home	1122	28.5	9.8	1.11 (0.87-1.41)	*1.40 (1.04-1.89)*
- Hospital (ref)	1277	28.7	9.0	1	1
Hospitalization in the last month of life?					
- Yes	1815	35.5	17.0	*1.43 (1.22-1.67)*	*1.28 (1.06-1.53)*
- No (ref)	3027	64.5	12.5	1	1

Table 2 (continued): Patient and care characteristics associated with involvement of palliative care and pain specialists in the last month of life

Palliative care and pain specialist involvement					
	n	**% (column)**	**% (row)**	**Univariate logistic regression OR (95% CI)**	**Multivariate logistic regression OR (95% CI)**
Was care prior to death aimed at palliation or comfort?					
- Yes, during the last weeks/months of life	2626	47.9	20.7	*5.74 (4.42-7.46)*	*3.98 (2.93-5.41)*
- Yes, during the last days of life	892	21.4	14.2	*3.65 (2.72-4.91)*	*3.11 (2.26-4.27)*
- No, or only in the last hours of life	1136	30.7	4.3	1	1

All percentages are weighted for sampling fractions, non-response, and random sampling deviations, to make them representative for all non-sudden deaths in the year studied
ref reference category, *OR (95% CI)* odds ratio's and 95% confidence intervals

Involvement of psychological or spiritual caregivers was most common for patients aged 64 -79 years (17%, OR=1.32, CI 1.09-1.59), for female patients (19%, OR=1.31, CI 1.11-1.54) and for patients who died in a nursing home (33%, OR=3.67, CI 2.83-4.75). Psychological or spiritual caregivers were also more often consulted for patients for whom care had been aimed at palliation during the last weeks and months of life (23%, OR=2.19, CI 1.73-4.75) (Table 3).

Table 3: Patient and care characteristics associated with involvement of psychological and spiritual caregivers in the last month of life

Psychological and spiritual caregiver involvement					
	n	**% (column)**	**% (row)**	**Univariate logistic Regression OR (95% CI)**	**Multivariate logistic Regression OR (95% CI)**
Overall	5062		16.3		
Age					
0-64	1312	16.0	13.0	*0.73 (0.58-0.91)*	1.16(0.89-1.51)
64-79	1663	30.2	16.7	0.98 (0.83-1.15)	*1.32 (1.09-1.59)*
> 80 (ref)	2087	53.8	17.0	1	1
Sex					
Female	2518	53.5	19.0	*1.53 (1.32-1.78)*	*1.31 (1.11-1.54)*
Male (ref)	2544	46.5	13.2	1	1

Table 3 (continued): Patient and care characteristics associated with involvement of psychological and spiritual caregivers in the last month of life

Psychological and spiritual caregiver involvement

	n	**% (column)**	**% (row)**	**Univariate logistic Regression OR (95% CI)**	**Multivariate logistic Regression OR (95% CI)**
Cause of Death					
Cardiovascular disease	543	16.5	12.5	*0.63 (0.50-0.79)*	1.01 (0.79-1.29)
Cancer	2925	37.2	15.4	*0.80 (0.69-0.94)*	1.16 (0.93-1.44)
Other or unknown (ref)	1594	46.3	18.4	1	1
Dementia					
Yes	4104	23.0	26.9	*2.35 (2.02-2.75)*	1.08 (0.87-1.34)
No (ref)	739	77.0	13.5	1	1
Place of death					
Home and residential home	2663	42.8	10.1	1.17 (0.93-1.45)	0.78 (0.60-1.01)
Nursing home	1122	28.5	33.0	*5.10 (4.15-6.26)*	*3.67 (2.83-4.75)*
Hospital (ref)	1277	28.7	8.8	1	1
Hospitalization in the last month of life?					
Yes	1815	35.5	13.6	*0.71 (0.61-0.83)*	1.09 (0.91-1.32)
No (ref)	3027	64.5	18.1	1	1
Was care prior to death aimed at palliation or comfort?					
Yes, during the last weeks/ months of life	2626	47.9	22.8	*2.82 (1.22-1.97)*	*2.19 (1.73-2.76)*
Yes, during the last days of life	892	21.4	13.9	*1.55(1.22-1.97)*	1.26 (0.98-1.63)
No, or only in the last hours of life	1136	30.7	9.5	1	1

All percentages are weighted for sampling fractions, non-response, and random sampling deviations, to make them representative for all non-sudden deaths in the year studied
ref reference category, *OR (95% CI)* odds ratio's and 95% confidence intervals

Associations between involvement of supportive caregivers and end of life care and end-of-life decision making

In a multivariable logistic regression model, involvement of pain or palliative care specialists was associated with an increased likelihood that the patient had received morphine in the last 24 hours before death (OR=2.03, CI 1.59-2.59), continuous deep sedation (OR=2.26, CI 1.80-2.74), euthanasia or physician assisted suicide (OR=1.47, CI 1.06-2.03) and intensive alleviation of symptoms with a potential risk of hastening death (OR=1.39, CI 1.17-1.64) (Table 4). Involvement of psychological or spiritual caregivers was associated with a higher likelihood that the patient had received morphine in the last 24 hours before death (OR=1.72, CI 1.40-2.11), intensive alleviation of symptoms (OR=1.51, CI 1.29-1.76) and that potentially life-prolonging treatment had been withdrawn or withheld (OR=1.26, CI 1.08-1.48).

Table 4: Association between involvement of supportive care professionals and use of morphine, continuous deep sedation and end-of-life decisions

Involvement of supportive caregivers		N= 4930	Morphine in the last 24 h before death		Continuous deep deep sedation		Euthanasia or physician assisted suicide		Intensive alleviation of symptoms		Forgoing life prolonging treatment	
			%	OR(CI)	%	OR(CI)	%	OR(CI)	%	OR(CI)	%	OR(CI)
Palliative care / pain specialist	Yes	958	88.1	2.03 (1.59-2.59)	28.5	2.26 (1.80-2.74)	8.7	1.47 (1.06-2.03)	63.7	1.39 (1.17-1.64)	36.1	0.95 (0.80-1.13)
	No (ref)	3972	73.6	1	13.6	1	2.9	1	55.4	1	48.5	1
Psychological / spiritual caregiver	Yes	788	84.2	1.72 (1.40-2.11)	15.4	1.18 (0.95-1.45)	3.9	1.11 (0.72-1.73)	65.2	1.51 (1.29-1.76)	52.0	1.26 (1.08-1.48)
	No (ref)	4142	73.9	1	15.7	1	2.9	1	54.9	1	45.7	1

All percentages are weighted for sampling fractions, non-response, and random sampling deviations, to make them representative for all non-sudden deaths in 2010

ref reference category, *OR (95% CI)* odds ratio's and 95% confidence intervals

Discussion

Involvement of supportive care givers in the last month of life.
This study shows that in the Netherlands supportive care specialists are involved in patients' care in the last month of life in a minority of cases: a palliative care team or consultant was involved in 12% of all non sudden deaths, a pain specialist in 3%, a psychologist or psychiatrist in 6% and a spiritual caregiver in 13%. The involvement of palliative care teams or consultants is low compared to other countries, e.g. Australia, were specialists palliative care services are involved in approximately 37.5% of the total number of people who are expected to die each year.(27)

We found substantial differences in the use of supportive caregivers in different patient groups. Psychological and spiritual caregivers were more often consulted in patients who die in the nursing home. This is probably due to the availability of these caregivers in nursing homes where, besides elderly care physicians, psychologists, pastoral workers and other disciplines are part of the multidisciplinary team.(28) Palliative care and pain specialists were more often consulted for younger patients and patients who died of cancer, whereas patients with dementia had a lower likelihood of involvement of these caregivers. It can be questioned whether this is due to different palliative care needs, e.g. because of differences in disease trajectories or in the complexity of the patient's situation, or whether this reflects potential barriers in access to palliative care services. Substantial symptom burden has been reported for patients with varying diagnoses, such as cancer, dementia and COPD or heart failure.(6-8) It is known that there are many barriers to the adequate use of palliative care, such as late referral, lack of physicians knowledge on palliative care and communication skills, the view that involving palliative care specialists is a signal that all hope for a patient is given up, health care providers' interpretation of the death of a patient as a failure and the lack of awareness of the availability of palliative care services.(29-34) This may probably explain the fact that not all patients have equal access to palliative care. For elderly patients, ethnic minority groups, patients with lower socioeconomic status and other disadvantaged groups, poor access to palliative care has been reported before.(35) Some subpopulations are less often referred to palliative care services such as patients with non-cancer diagnoses.(36, 37)
On the other hand, not everyone facing a life-limiting illness needs specialist palliative caregivers.(36) In the Netherlands all health care professionals are supposed to be capable of providing general palliative care, which can, when necessary, be complemented by specialist palliative care that should be readily available.(38) This is in line with a

model described by Quill and Abernethy that distinguishes primary palliative care (skills all clinicians should have) from specialist palliative care (skills for managing more complex and difficult cases), coexisting and supporting each other.(39) However, in the Netherlands, it is not yet clear how basic or general palliative care and specialist palliative care are defined and can be distinguished. In this study, the need for specialist palliative care was not investigated, and therefore we cannot draw firm conclusions regarding under- or overuse of supportive care.

Supportive care and end-of-life care and decisions making

In order to prevent or alleviate suffering at the end of life, end-of-life decisions can be made, such as forgoing burdensome treatment and intensifying alleviation of pain or other symptoms. In this study we found that involvement of supportive caregivers was associated with a higher likelihood of use of morphine in the last 24 hours before death and with patients receiving intensive forms of alleviation of symptoms, such as continuous deep sedation. This is not surprising as supportive caregivers will be consulted more often in complex situations. The latter may be related to the requirement in the national guideline for use of palliative sedation of presence of refractory symptoms.(40) When suffering becomes unbearable, patients may ask for the hastening of death, which is allowed under strict regulation in the Netherlands.(26) Involvement of pain and palliative specialists was also associated with a higher likelihood of receiving euthanasia. This is in line with an earlier study in which involvement of palliative care teams and psychiatrists was positively associated with patients requesting euthanasia.(41) As our study had a cross sectional design, we cannot conclude that there is a causal relationship between involvement of supportive care professionals and end-of-life decisions, but our data suggest that the involvement of supportive caregivers does not prevent euthanasia or other end-of life decisions.

Strengths and limitations.

A strength of this study is the large number of deaths that were studied (n=6263). Furthermore, cases were obtained from a nationwide, representative sample and the response rate was high (74%).

A limitation is that the questionnaire was filled in by the physician who attended patients' death. This may not always have been the physician who was the attending caregiver in the period that preceded death, which may imply that the physician might not have been aware of all caregivers that were involved. This may have resulted in an underreporting of the involvement of the different caregivers, especially of spiritual caregivers, because physicians may not always be aware of the involvement of spiritual caregivers. In our questionnaire, we combined ‘psychologists’ and ‘psychiatrists’. It may not have been proper to combine psychologists and spiritual caregivers (non-physicians), with psychiatrists (physicians). Furthermore, we did not assess the effects of the involvement of these supportive caregivers, e.g. on patients’ quality of life.

Recommendations

This study provides insight in patterns in the use of supportive and palliative care in the last month of life. Further insight in whether people with life-limiting illnesses who do not access specialized palliative or supportive care services have unmet needs is crucial in planning and evaluating palliative care. It would be desirable to structurally monitor the use of palliative and supportive care on a regular basis.

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CHAPTER 10

Obligatory consultation of an independent physician on euthanasia requests in the Netherlands: what influences the SCEN physicians judgment of the legal requirements of due care?

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Abstract

Background

In the Netherlands, euthanasia is allowed if physicians adhere to legal requirements. Consultation of an independent physician is one of the requirements. SCEN (Support and Consultation on Euthanasia in the Netherlands) physicians have been trained to provide such consultations.

Objective

To study why euthanasia requests are sometimes judged not to meet requirements of due care and to find out which characteristics are associated with the SCEN physicians' judgments.

Methods

During 5 years (2006, 2008-2011) standardized registration forms were used for data-collection. We used multilevel logistic regression analysis to assess the associations of characteristics and SCEN physicians' judgments.

Results

We analyzed 1631 euthanasia requests, involving 415 SCEN physicians. Patient characteristics that were associated with a lower likelihood to meet due care requirements were: being tired with life, depression and not wanting to be a burden. Physical suffering and higher patient age were related to greater chances of meeting the requirements. There was no clear association between SCEN physicians' characteristics and their judgment.

Conclusion

Psychological suffering involves a greater chance that SCEN physicians judge that requirements for due care are not met. The association between SCEN physician characteristics and the judgment of euthanasia requests is limited, suggesting uniformity in their judgment.

Introduction

In 2002 the euthanasia law regulating the ending of life by a physician at the request of a patient with unbearable suffering came into effect in the Netherlands. The act legalized an existing practice, since physicians had not been prosecuted as long as the actions were consistent with standards of care that had been established in the early 1990s.(1) Euthanasia is defined as the administering of lethal drugs by a physician with the explicit intention to end a patient's life on that patient's explicit request. In physician-assisted suicide, that is subject to the same law, the patient self-administers lethal medication that was prescribed intentionally by a physician.(2) In the euthanasia law it is stated that physicians will not be prosecuted when they meet a specific set of requirements of due care (See box 1).

Box 1: Due care requirements of euthanasia and physician-assisted suicide as laid down in the Dutch Euthanasia Act.

a. the physician must be convinced that the patient's request is voluntary and well considered;
b. the physician must be convinced that the patient's suffering is unbearable and without prospect of relief;
c. the physician must be convinced that the patient is informed about his/her situation and prospects;
d. the physician together with the patient must be convinced that there is no reasonable alternative solution for the situation;
e. at least one other independent physician must see the patient and must give a written statement containing his judgment of the four previous requirements;
f. the ending of life must be performed in a professional and careful way.

One of the requirements of due care involves consultation of at least one other independent physician. Such consultation prior to the act is considered to be an important safeguard, in addition to the review of cases by a multidisciplinary review committee after the act.(3) The consulting physician must see the patient and must give a written statement of his judgment of the other requirements of due care. The attending physician must inform the consultant about the patient's situation and provide him with the patient's medical file.(3) In order to guarantee that consulting physicians provide independent and skilled advice, the Royal Dutch Medical Association in 1997 initiated the project 'Support and Consultation on Euthanasia in Amsterdam' (SCEA) to train consulting physicians. After a positive evaluation in 1999, the project was gradually implemented throughout the Netherlands; it is now referred to as 'Support and Consultation on Euthanasia in the Netherlands' (SCEN).(4) In SCEN, which can be compared to the Belgian consultation service LEIF (Life End Information Forum)(5-7), physicians follow a special 3 day-training program. SCEN physicians are mainly general practitioners, but some are nursing home physicians or medical specialists. In a recent position paper of the Dutch Royal Medical Association (8) it is stated that it is the task of the SCEN physician 'to assess the case within the framework of the Euthanasia Law, to which end the SCEN physician must test the requirements of due care against the Euthanasia Law in as professional and objective a manner as possible'. Acting in this capacity, the SCEN physician must 'step outside the normative framework for judging euthanasia requests that he would apply were he asked to perform euthanasia himself.' When confronted with a euthanasia request of a patient different attending physicians can come to different conclusions regarding granting or refusing the request because next to judging whether the judicial requirements of due care, they also have to judge whether it falls within their own boundaries. This in contrast to SCEN physicians who only have to assess the judicial requirements of due care. This implies that physicians should not draw different conclusions in similar cases. In a study among SCEN-physicians it was found that SCEN physicians also consider this uniformity in judgment important (9), as it contributes to the quality of the consultation which is the aim of the SCEN project.(4) In addition the interaction with the SCEN physician can be supportive to the attending physician, as performing euthanasia can have a major impact on physicians.(10)

In an evaluation of the euthanasia law, it was shown that in 2010 80% of all formal consultations in cases of euthanasia were provided by SCEN physicians.(11) It is known that SCEN physicians judge that requirements of due care are met in the majority of cases. However, in about 20% of all cases SCEN physicians judge that the requirements of due care are not (or not yet) met.(12) Factors contributing to SCEN physicians' judgment have never been studied. The aim of this study is to study why requests are sometimes judged not to meet requirements of due care and to find out which patient or SCEN physician characteristics are associated with the judgments of SCEN physicians. Bearing in mind the importance of uniformity of SCEN consultations finding no association for SCEN physician characteristics and an association for patient characteristics would be a sign of quality of consultations.

Methods

Study design and data collection

We performed an analysis of data that were collected in a repeated cross-sectional survey among SCEN physicians in the Netherlands, from 2006 through 2011. Each year, all registered SCEN physicians received a postal questionnaire on their most recent consultation. Response rates varied from 79%-86% (Table 1). For 2007, the questionnaire lacked detailed information about the SCEN physicians' identity. We therefore excluded all data from 2007. In total, we analyzed 1640 questionnaires that were completed by 415 SCEN physicians, of which 9 contained missing data. In the analysis, we only used cases with complete data (n=1631). In 2008, the questionnaire assessed SCEN physicians' characteristics, such as age, sex, specialty, number of years working as a SCEN physician, additional education in end-of-life care and whether the SCEN physician also worked as a palliative care consultant. Based on the unique SCEN physicians' unique numbers, these characteristics could be extrapolated to other years.

Table 1: Response rates to the yearly postal questionnaires that were send out to all Dutch SCEN physicians.

Year	Number of active SCEN physicians in the Netherlands	Response	Response rate
2006	508	434	85%
2008	594	508	86%
2009	555	452	81%
2010	566	447	79%
2011	598	494	83%

Measurement instrument / questionnaire

Questions were asked about the number of consultations over the past year and the setting in which they were provided. Specific questions were asked about the most recent consultation. These questions concerned characteristics of the case, such as the patient's age, gender and diagnosis, reasons for the request, the willingness of the attending physician to grant the request and the SCEN physician's judgment (requirements for due care met versus requirements for due care not (yet) met).

Statistical analysis

Comparisons were made between cases in which the SCEN physician judged that the requirements of due care were met and cases in which the requirements were judged not to be met. We performed multilevel logistic regression analyses to identify factors that were associated with these judgments. Whereas physicians could have judged more than one case, the multilevel models took possible clustering within SCEN physicians (intraclass correlation was 4%) into account.

Results

SCEN physicians' arguments to judge that requirements of due care were not met

In 20% (n=320) of all requests (n=1631), requirements of due care were not met according to the SCEN physician (Table 2). The most common argument why SCEN physicians thought that the requirements were not met was that they thought that there was 'no unbearable suffering' (n=271, 70%), 'no well-considered request' (n=94, 30%), or that 'other treatment options were still available'(n=58, 19%).

Table 2: SCEN physicians' arguments why requirements of due care were judged not to be met

	n (%)
Requirements of due care were judged to be met	1311 (80)
Requirements of due care were judged *not*[a] to be met	320 (20)
SCEN physicians' arguments why requirements of due care were judged not to be met[b]	
- No unbearable suffering	271 (70)
- No suffering without prospect of relief	26 (8)
- No voluntary request	17 (6)
- No well considered request	94 (30)
- Other treatment options were still available	58 (19)

[a] This concerns cases in which requirements were 'not' or were 'not yet' met (e.g. when the symptom burden is likely to increase in the future).

[b] More than one answer possible.

Association between SCEN physicians' characteristics and SCEN physicians' judgment of the requirements of due care

SCEN physicians were mostly male (n=304, 73%), general practitioner (n=318, 78%), and had been working for 4 – 8 years as a SCEN physician (n=229, 55%). Most of them had followed additional end-of-life education (n=305, 74%) in addition to their training as a SCEN physician; 14% (n=58) also worked as a palliative care consultant (Table 3). Of all

SCEN physician characteristics, only older age was associated with a lower likelihood that the requirements of due care were judged not to be met (Table 3).

Association between patient characteristics and SCEN physicians' judgment of the requirements of due care

Most patients were diagnosed with cancer (n=1309, 80%); others were diagnosed with cardiovascular diseases such as heart failure or a cerebrovascular accident (n=60, 4%), neurological diseases such as multiple sclerosis or amyotrophic lateral sclerosis (n= 60, 4%) or chronic obstructive pulmonary disease (n=45, 3%) (Table 4). Various reasons were underlying patients' requests for euthanasia. The most frequently mentioned reasons were 'overall weakness' (n=964, 59%), 'loss of dignity' (n=875, 54%), 'knowing that suffering will not get better' (n=735, 45%), 'dependency' (n=511, 31%) and 'pointless suffering' (n=446, 27%). Less frequent reasons were 'depression' (n=78, 0.5%), 'not wanting to be a burden for family' (n=78, 5%), 'being tired with life' (n=93, 6%), 'vomiting' (n= 160, 10%) and 'invalidity' (n=176, 11%).

Compared to cancer patients, being diagnosed with MS or ALS was associated with a higher likelihood that requirement of due care were judged not to be met in the univariate analyses (Table 4). Higher patient age and suffering including 'loss of dignity', 'overall weakness', 'pointless suffering', 'knowing that suffering will not get better', 'pain', 'vomiting' and 'dependency' were associated with a lower likelihood that requirements of due care were not being met. 'Being tired with life', 'depression' and 'not wanting to be a burden for family' were associated with a higher likelihood that the requirements of due care were judged not to be met.

Association between patient and SCEN physicians' characteristics and SCEN physicians' judgment in the multivariable analysis

When we combined the physician and patient characteristics that were associated with the SCEN physicians' judgment in a multivariable model (Table 3 and Table 4), the following patient characteristics remained significantly associated with the physician's judgment: the reason for the patient's request being 'being tired with life' (OR=2.66) 'not wanting to be a burden' (OR=2.86) or 'depression' (OR=8.21) involved a statistically significantly higher likelihood that the request was judged not to meet the requirements of due care.

Patients with older age (OR=0.85) and patients who requested euthanasia because of 'loss of dignity' (OR=0.57), 'overall weakness' (OR=0.39), 'pointless suffering' (OR=0.53), 'knowing that suffering will not get better' (OR=0.57), 'pain' (OR=0.55) and 'vomiting'

(OR=0.42), 'dependency' (OR=0.67) or 'dyspnea' (OR=0.67) were less likely to have their request judged as not meeting the requirements of due care. Regarding the SCEN physicians' characteristics, only older SCEN physicians' age involved a marginally significant lower likelihood that the request was judged not to meet requirements of due care (OR=0.85).

Table 3: Characteristics of 415 SCEN physicians and multilevel univariate and multivariable odds ratios for the likelihood that the legal requirements of due care were judged not to be met

	Physicians N=415 n (%)	Univariate Odds ratio (95% CI)	Multivariable Odds ratio (95% CI)
Age[a]	56 (52-60)[b]	0.82 (0.75-0.89)	0.85 (0.73-1.00)
Sex			
- Male	304 (73)	1	1
- Female	111 (27)	1.01 (0.76-1.35)	0.95 (0.69-1.31)
Specialty			
- General Practitioner	318 (77)	1	1
- Nursing home physician	45 (11)	1.29 (0.86-1.92)	1.50 (0.94-2.39)
- Medical specialist	52 (12)	1.04 (0.70-1.56)	0.90 (0.56-1.44)
Number of years working as a SCEN physician			
< 4	85 (21)	1	1
4-8	229 (55)	0.74 (0.51-1.06)	0.84 (0.55-1.28)
>8	101 (24)	0.69 (0.47-1.02)	0.89 (0.55-1.45)
Additional education in end-of-life care			
- Yes	305 (74)	0.95 (0.71-1.27)	0.94 (0.68-1.31)
- No	101 (26)	1	1
SCEN physician also works as a palliative care consultant?			
- Yes	58 (14)	1	1
- No, not any more	32 (7)	1.12 (0.76-1.64)	0.94 (0.48-1.83)
- No	325 (79)	1.00 (0.54-1.83)	0.11 (0.73-1.70)

[a] Odds ratio per 10 years

[b] Median and interquartile range

Table 4: Characteristics of patients who requested for euthanasia and multilevel univariate and multivariable odds ratios for the likelihood that the legal requirements of due care were judged not to be met

	Cases N=1621 n (%)	Univariate Odds ratio (95% CI)	Multivariable Odds ratio (95% CI)
Age[a]	69 (60-78)[b]	0.90 (0.88-0.93)	0.85 (0.83-0.88)
Sex			
- Male	869 (53)	1	1
- Female	762 (47)	1.08 (0.84-1.38)	1.02 (0.78-1.34)
Diagnosis			
- Cancer	1309 (80)	1	1
- Hart failure/ CVA	60 (4)	1.04 (0.53-2.05)	1.38 (0.64-2.94)
- MS / ALS	60 (4)	1.91 (1.07-3.40)	1.52 (0.80-2.89)
- COPD	45 (3)	1.50 (0.74-3.03)	1.47 (0.68-3.22)
- Other	156 (10)	2.01 (1.38-2.93)	1.61 (1.02-2.52)
Loss of dignity			
- Yes	875 (54)	0.57 (0.44 -0.73)	0.57 (0.43-0.76)
- No	756 (46)	1	1
Overall weakness			
- Yes	964 (59)	0.34 (0.26-0.44)	0.39 (0.29-0.51)
- No	667 (41)	1	1
Being tired with life			
- Yes	93 (6)	2.70 (1.73-4.23)	2.66 (1.56-4.53)
- No	1538 (94)	1	1
Pointless suffering			
- Yes	446 (27)	0.54 (0.39-0.74)	0.53 (0.38-0.75)
- No	1185 (73)	1	1
Knowing that suffering will not get better			
- Yes	735 (45)	0.53 (0.40-0.68)	0.57 (0.43-0.75)
- No	896 (55)	1	1
Pain			
- Yes	504 (31)	0.61 (0.45-0.81)	0.55 (0.40-0.75)
- No	1127 (69)	1	1

Table 4 (continued): Characteristics of patients who requested for euthanasia and multilevel univariate and multivariable odds ratios for the likelihood that the legal requirements of due care were judged not to be met

	Cases N=1621 n (%)	Univariate Odds ratio (95% CI)	Multivariable Odds ratio (95% CI)
Vomiting			
- Yes	160 (10)	0.42 (0.24-0.73)	0.42 (0.24-0.75)
- No	1471 (90)	1	1
Fear of suffocation			
- Yes	187 (12)	1.25 (0.86-1.82)	1.09 (0.71-1.66)
- No	1444 (89)	1	1
Invalidity			
- Yes	176 (11)	0.69 (0.44-1.07)	0.65 (0.40-1.06)
- No	1455 (89)	1	1
Depression			
- Yes	8 (0)	13.63 (2.64-70.28)	8.21 (1.05-64.44)
- No	1623 (100)	1	1
Dependency			
- Yes	511 (31)	0.68 (0.51-0.90)	0.67 (0.49-0.92)
- No	1120 (69)	1	1
Not wanting to be a burden for family			
- Yes	78 (5)	2.75 (1.70-4.45)	2.86 (1.65-4.94)
- No	1553 (95)	1	1
Dyspnea			
- Yes	295 (18)	0.81 (0.57-1.13)	0.67 (0.46-0.99)
- No	1336 (82)	1	1

[a] Odds ratio per 10 years

[b] Median and interquartile range

Discussion

SCEN physicians’ reasons why requirements of due care are not met

The most common reason for SCEN physicians to judge that requirements of due care were not met is that they judge that there is ‘no unbearable suffering’ (70%), which is in line with other studies.(12, 13) The need to relieve patients’ unbearable suffering is an important principle underlying the Dutch Euthanasia Act. It is the consulting physician's task to judge whether or not the suffering of the patient can be considered as unbearable, based on one or more private conversations with the patient and on the medical file. Assessing the unbearability of suffering has been shown to be difficult.(14) In a study among 2100 Dutch physicians, 25% had experienced problems in the decision-making on whether to comply with a euthanasia request; 79% of them indicated to have had problems with judging whether or not the patient's suffering was unbearable and hopeless.(14)

It can be questioned if it is in principle possible to make a proper judgment of whether a patient suffers unbearably. The judgment of suffering ultimately depends on the experience of the person who is suffering, and hence is an individual matter.(15) What can be objectively determined is the underlying disease and the accompanying symptoms and loss of function. The Dutch philosopher Wijsbek states that it is possible to make an assessment of another person's suffering because our inner self is not inaccessible for others. As we belong to the same species, with the same senses and the same brain, we in principal can take each other's perspectives.(16) In order to do so properly, two requirements have to be met. First, physicians have to fully inform their patients and to discuss their patients' values. Second, patients' values and wishes have to be reasonable within the current societal context. As SCEN physicians see high numbers of patients who request for euthanasia and because they have received formal training in how to assess these requests, they are expected to have extensive experience with judging the unbearability of patients' suffering and thus to be able to make a proper judgment.

SCEN physician and patient characteristics contributing to whether or not the SCEN physician judges that requirements of due care are met.

According to SCEN physicians in this study, the main reasons for patients to request euthanasia were 'overall weakness' (59%), 'loss of dignity' (54%) and 'knowing that suffering will not get better' (45%). This is in concordance with previous research.(13,17) Our study shows that SCEN physicians' characteristics such as sex, years of experience and specialty, are not associated with their judgments. In the univariate analysis only SCEN physician's age was associated with their judgment, this remained marginally significant in the multivariate analysis. This suggests that overall SCEN physicians are successful in their effort to reach uniformity in their judgment.

Several patient characteristics were associated with the SCEN physicians' judgments.

Patients for whom 'being tired with life', 'depression' or 'not wanting to be a burden for family' was a reason for their request for euthanasia had a decreased likelihood that their request was judged to meet the requirements of due care. On the other hand, patients for whom pointless suffering, knowing that suffering will not get better, loss of dignity and physical symptoms (overall weakness, pain, vomiting, dependency and dyspnea) were reasons to request for euthanasia were more likely that their request was considered to meet the requirements of due care. Other studies have investigated why requests for euthanasia did or did not result in euthanasia. Factors associated with requests resulting in euthanasia are the patient having physical symptoms such as pain, nausea and dyspnea, not having depressive symptoms, no alternative treatment being available and the patient being competent at the time of the request.(18, 19) A study by Haverkate et al. (2000) found that 'weariness of life' and 'not wanting to become a burden on the family' were relatively common among refused requests.(17) Compared to patients whose requests were granted, patients whose requests were refused more often had mental health problems and were less likely to be clearly in the terminal phase.(17) Meier et al. (2003) also studied patients characteristics associated with physician-assisted suicide and found that physicians were more likely to honor requests for physician-assisted suicide from patients who were in severe pain or discomfort, who had a life expectancy of less than one month, and who were not believed to be depressed at the time of the request.(20) Onwuteaka-Philipsen et al. found that diagnosis (cancer, nervous system) and place of death (home) were also associated with requests being granted.(18)

These studies are in line with the results of our study. The findings seem to show that mental health problems are likely to increase that chance that euthanasia requests are refused.

Strengths and limitations

A strength of this study is the large number of cases involved and the long period of investigation. A limitation might be that SCEN physicians were asked to remember the last request. There might be some bias towards remembering requests that were easier and qualified for euthanasia. However, because the questionnaires were filled in anonymously, this bias is probably limited.

Another limitation is that only SCEN physicians were questioned and not the attending physician or the patient. In addition, this study does not allow to assess whether the assessment of the requirements of due care was done according to how it is meant in the law. However, from the evaluation of the euthanasia law we know that in most reported cases of euthanasia there was a SCEN consultation and that euthanasia review committees almost always judge that the criteria for due care are met. On the other side, it is less clear whether in cases in which the SCEN physician considered the criteria for due care not to be met, a euthanasia review committee would draw the same conclusion.

Conclusion

SCEN physicians judge that requirements of due care are not met in 20% of all requests for euthanasia for which they are asked to provide a second independent judgment. In 70% of these cases they judged that the requirement concerning unbearable suffering was not met. Older patient age and specific types of suffering such as depression, being tired with life and not wanting to be a burden for family involve a greater chance that SCEN physicians judge that requirements of due care are not met. Of the SCEN physician characteristics, only older age seems to slightly increase the chance that the requirements of due care are judged to be met. This suggests they are successful in achieving the uniformity of judgment they strive for. Uniformity in judgment is important to guarantee the quality consultation, which then can contribute to the quality of euthanasia and physician assisted suicide. These results can inform the debate in countries in which the regulation of euthanasia is a topic of debate.

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CHAPTER 11

The effects of advance care planning on end-of-life care: a systematic review

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Abstract

Background

Advance care planning is the process of discussing and recording patient preferences concerning goals of care for patients who may lose capacity or communication ability in the future. Advance care planning could potentially improve end-of-life care, but the methods/tools used are varied and of uncertain benefit. Outcome measures used in existing studies are highly variable.

Aim

To present an overview of studies on the effects of advance care planning and gain insight in the effectiveness of different types of advance care planning.

Design

Systematic review.

Data sources

We systematically searched PubMed, EMBASE and PsycINFO databases for experimental and observational studies on the effects of advance care planning published in 2000–2012.

Results

The search yielded 3571 papers, of which 113 were relevant for this review. For each study, the level of evidence was graded. Most studies were observational (95%), originated from the United States (81%) and were performed in hospitals (49%) or nursing homes (32%). Do-not-resuscitate orders (39%) and written advance directives (34%) were most often studied. Advance care planning was often found to decrease life-sustaining treatment, increase use of hospice and palliative care and prevent hospitalization. Complex advance care planning interventions seem to increase compliance with patients' end-of-life wishes.

Conclusion

The effects of different types of advance care planning have been studied in various settings and populations using different outcome measures. There is evidence that advance care planning positively impacts the quality of end-of-life care. Complex advance care planning interventions may be more effective in meeting patients' preferences than written documents alone. More studies are needed with an experimental design, in different settings, including the community

Introduction

People increasingly wish to have some control over their last phase of life, which includes decision making about medical treatment and its aims.(1-4) However, patients may become incapable of making treatment decisions near the end of life, e.g. due to delirium or cognitive impairment.(5) Advance care planning (ACP) is a means of extending the autonomy of patients to stages in life where they have become incompetent. It can be defined as "*a process of discussion about goals of care and means of setting on record preferences for care of patients who may lose capacity or communicating ability in the future*".(6) ACP enables patients and their families to consider what care and treatments might or might not be acceptable, and to try and make plans in line with their wishes. ACP primarily focuses on planning for the possibility of decisional incapacity but can also serve as a basis for decision-making in patients who retain capacity. Originally, the focus of ACP was on the completion of written documents, such as advance directives (including living wills and durable powers of attorney for health care), do-not-resuscitate (DNR) orders and do-not-hospitalize (DNH) orders. Nowadays, the focus of advance care planning is not only on the completion of written forms, but also on the social process.(5)

ACP has been receiving increasing attention since the 1990s. The pros and cons of advance care planning have been much debated.(2, 7-9) The 'Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment' (SUPPORT), an important study on the effects of ACP, did not show any effect of a complex ACP intervention on outcomes such as use of mechanical ventilation, days spent in an intensive care unit (ICU), or level of reported pain.(10) This latter study and others (11, 12) have raised questions regarding the effects of advance care planning.(13-15) For example, it may be ineffective because advance directives are often not sufficiently specific, and clinical reality is often different from the hypothetical situation that is addressed in advance care planning. Furthermore, being engaged in advance care planning is suggested to be stressful for patients (16), which may result in less effective implementation. However, more recent studies have shown that advance care planning is able to improve compliance with patients' end-of-life wishes, and patients' and families' satisfaction with care, and that it reduces family stress, anxiety and depression.(17, 18)

During the past year, the effect of ACP has been much debated (13-15). Studies on ACP and its effects involve many different types of ACP and many different outcome measures, all of which makes it difficult to draw general conclusions regarding its usefulness in clinical practice. ACP could potentially improve end-of-life care but the methods and tools used are varied and of uncertain benefit.

The aim of this study is to provide an overview of recently published papers about studies on the effects to alter end-of-life care and to gain insight in the effectiveness of different types of advance care planning. The research question addressed is 'What are the effects of ACP on end-of-life care?' Our aim is to investigate which aspects of end-of life care, such as medical treatment, place of care and quality of life, are affected by the use of different types of ACP.

Methods

Literature search

A systematic electronic search was conducted in the databases PubMed, EMBASE and PsycInfo. We included studies that were published in the English language from January 2000 until December 2012, in order to get an overview on effects of ACP over the last decade. Box 1 presents the search terms used.

In addition, we hand searched the Journal of the American Geriatric Society and the Journal of Palliative Medicine from 2009 to December 2012, because these two journals published the most hits in our systematic search. Finally, we also screened the references of the included papers.

Box 1: Search strategy for the current review

I.Pubmed
(advance care plan*[tw] OR advance health care plan*[tw] OR advance health-care plan*[tw] OR advance healthcare plan*[tw] OR advance medical plan*[tw] OR advance directive*[tw] OR living will*[tw] OR advanced care plan*[tw] OR advanced health care plan*[tw] OR advanced health-care plan*[tw] OR advanced healthcare plan*[tw] OR advanced medical plan*[tw] OR advanced directive*[tw] OR advance medical direct* [tw] OR advanced medical direct*[tw] OR healthcare prox* [tw] OR health care prox* [tw]OR do-not-resuscitate order[tw] OR DNR [tw] OR resuscitate order [tw] OR do-not-hospitalize order [tw] or DNH [tw] OR hospitalize order [tw] OR **"**Advance Care Planning"[Mesh] OR "Advance Directives"[Mesh] OR "Resuscitation Orders"[Mesh] OR "Living Wills"[Mesh]) AND (outcom*[tw] OR efficien*[tw] OR efficac*[tw] OR satisf*[tw] OR evaluation stud*[tw] OR clinical trial*[tw] OR randomi*[tw] OR comparative study [pt] OR evaluation studies [pt] OR epidemiologic studies [mh] OR multivariate analysis [mh]) AND 2000:2011/12/31[dp]

2.Embase
((advance* NEAR/3 (plan* OR directive*)):de,ab,ti OR (living NEAR/1 will*):de,ab,ti OR (health* NEAR/1 prox*):de,ab,ti OR (do-not-resuscitate order:de,ab,ti) OR (resuscitate order;de,ab,ti) OR (DNR:de,ab,ti) OR (hospitalize order:de,ab,ti) OR (do-not-hospitalize order;de,ab,ti) OR (DNH:de,ab,ti)) AND (outcom*:de,ab,ti OR efficien*:de,ab,ti OR efficac*:de,ab,ti OR satisf*:de,ab,ti OR (evaluation NEAR/1 stud*):de,ab,ti OR (clinical NEAR/1 trial*):de,ab,ti OR randomi*:de,ab,ti OR (prospect* NEAR/1 stud*):de,ab,ti OR (retrospect* NEAR/1 stud*):de,ab,ti OR (emper* NEAR/1 stud*):de,ab,ti OR (follow** NEAR/1 stud*):de,ab,ti OR (longit* NEAR/1 stud*):de,ab,ti OR (quant* NEAR/1 stud*):de,ab,ti OR (multivariatet* NEAR/1 analys*):de,ab,ti OR (epidemiol* NEAR/1 stud*):de,ab,ti) AND [2000-2012]/py

3.Psychinfo
(advance care plan* or advanced care plan* or advance health care plan* or advanced health care plan* or advance health-care plan* or advanced health-care plan* or advance healthcare plan* or advanced healthcare plan* or advance medical plan* or advanced medical plan* or advance direct* or advanced direct* or advance medical direct* or advanced medical direct* or living will* or health care prox* or healthcare prox* or health-care prox* or do-not-resuscitate order or DNR or resuscitate order or do-not-hospitalize order OR DNH or hospitalize order).mp.
limit 1 to (("0400 empirical study" or "0430 followup study" or "0450 longitudinal study" or "0451 prospective study" or "0452 retrospective study" or 1800 quantitative study or "2000 treatment outcome/randomized clinical trial") and yr="2000 - 2012")

Conducted on 20 May 2013.

Study selection

Two reviewers (AB and AvdH) used a stepwise procedure to identify relevant papers. In case of disagreement consensus was sought and readily achieved. Papers were included if they described comparative empirical research on the effects of ACP in which a comparison was made between patients who did and who did not participate in advance care planning. Effects had to pertain to medical treatment in the last phase of life, compliance with patients' end-of-life wishes, place of care and place of death, patients' and/or families' satisfaction with care, and prevalence or severity of symptoms. Both experimental and observational studies were included. Box 2 presents a detailed overview of the inclusion and exclusion criteria.

Box 2: In- and exclusion criteria

Inclusion criteria:

1. Articles describe empirical study on the effect of "advance care planning"
2. Studies concern quantitative research
3. Outcomes include:
    a. Effects on medical treatment in the last phase of life, including
        i. Compliance with patients' end-of-life wishes
        ii. Medical treatment and care (including use of life sustaining treatment, hospice and palliative care)
        iii. Hospitalization, hospital length of stay and place of death.
    b. Effects on quality of life and patients' and families satisfaction with care
    c. Effects on patients' and families' prevalence and/or severity of symptoms
4. Both intervention and observational studies with control group
5. Studies published in paper in English between January 2000 and December 2012

Exclusion criteria:

1. Studies in which advance care planning is only part of a more complex intervention, e.g. studies on the effect of palliative care consultation teams.
2. Studies on children
3. Studies on psychiatric patients
4. Studies on hypothetical situations (e.g. vignette studies)
5. Studies solely on effects on costs of care, on (understanding) patients' preferences or on completion of advance care planning documents.

Data extraction

Information was collected on general characteristics of the studies and on characteristics related to our research goal. Extracted information included study design (observational or experimental), study setting, number of patients studied, type of ACP, type of outcome measures, and results and conclusions. To get insight in the effects of different types of ACP, we distinguished between written advance directives (including living wills and durable powers of attorney), do-not-resuscitate orders and do-not-hospitalize orders (which can been seen as specific types of advance directives), and complex ACP interventions. Outcome measures included measures pertaining to medical treatment, compliance with patients' end-of-life wishes, place of care, place of death, patient or family satisfaction and symptoms. The effect of ACP as reported in the paper was classified as being associated with a decrease, increase or no difference in specific outcomes. Information was extracted using a standardized data extraction form.

Quality appraisal

We graded the level of evidence for each study using the criteria proposed by Higginson et al. (19), see Box 3. We have slightly adapted the criteria, as some were not mutually exclusive.

Box 3: Grade of evidence[a]

Grade I: RCT or RCT review
  IA Calculation of sample size[b] and accurate, standard definition of outcome variables.
  IB Accurate and standard definition of outcome variables.
  IC Neither of the above.

Grade II: Prospective study with a comparison group (non-randomized controlled trail, good observational study) or retrospective study which controls effectively for confounding variables
  IIA Calculation of sample size[b] and accurate, standard definition of outcome variables and adjustments for the effects of important confounding variables.
  IIB One or more of the above.
  IIC Neither of the above[c]

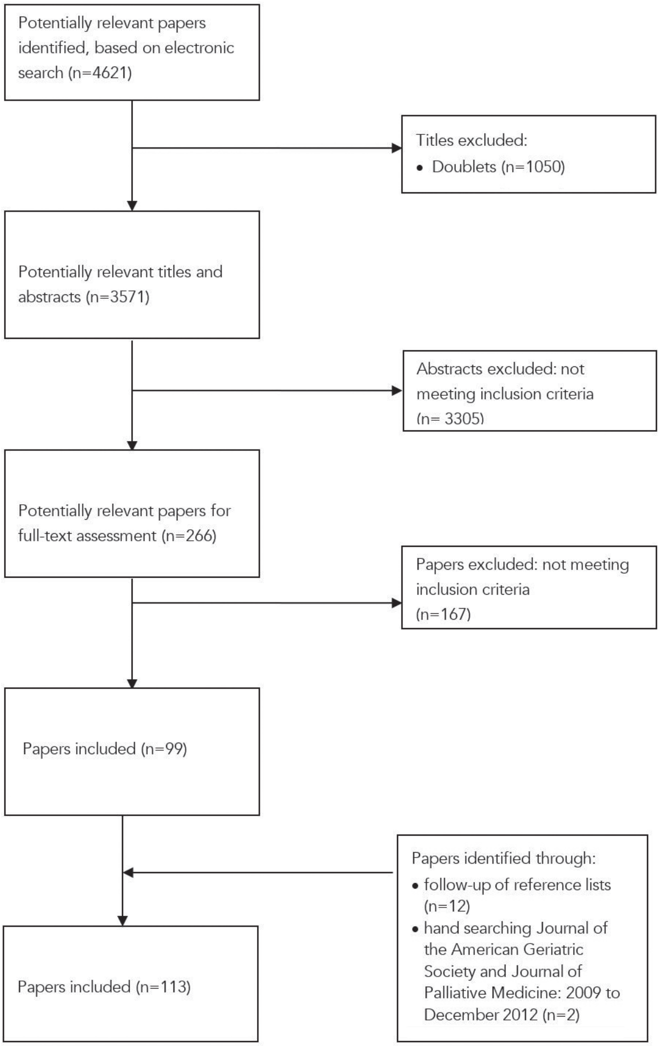
Grade III: Retrospective or observational or cross-sectional studies
  IIIA Comparison group, calculation of sample size b and accurate, standard definition of outcome variables.
  IIIB One or more of the above.
  IIIC Neither of the above.

[a] According to Higginson et al.(19)

[b] In case the number of respondents was 1000 or more, we considered these criteria to be met

[c] Category IIC was added

Figure 1: Flow of studies through the present review



Results

The database search yielded 3571 papers, after excluding 1050 duplicates. We excluded 3305 non-relevant papers based on titles or abstracts. In the second step, the 266 remaining papers were assessed based on the full text. Of these, 99 papers met our inclusion criteria. After screening the references of these remaining 99 papers, 12 papers could be added. Hand searching the Journal of the American Geriatric Society and the

Journal of Palliative Medicine for the years 2009 to 2012 resulted in two additional papers. Finally, 113 papers/studies were included. The process of study selection is presented in Figure 1.

Study characteristics

Table 1 shows the main characteristics of the 113 studies included in this review. Most studies were observational (107 studies), originated from the USA (91 studies), or Canada (5 studies), and were performed in institutional settings, such as hospitals (55 studies) or nursing homes (37 studies). Only 9 studies were performed in the community. Types of advance care planning studied included DNR orders (52 studies), completion of advance directives including living wills and durable powers of attorney (45 studies), DNH orders (16 studies) or complex advance care planning interventions (20 studies). In 16 studies more than one type of ACP was investigated. Studies were performed with different patient populations, such as patients with dementia or advanced cognitive impairment, patients with advanced cancer, patients hospitalized with an acute myocardial infarction, or trauma patients. The most frequently studied outcomes were medical treatment and place of care. Studies less often reported on symptoms, patient and family satisfaction, or compliance with patients' end-of-life wishes.

Table 1: Characteristics of studies on advance care planning (ACP)

Study Characteristics (N=113)		**n**	**(%)**
Type of study	Experimental	6	(5)
	Observational	107	(95)
Country	United States	91	(81)
	Canada	5	(4)
	Other	17	(15)
Setting	Community	9	(8)
	Nursing home	37	(32)
	Hospital (ex. ICU)	37	(33)
	Hospital ICU	18	(16)
	Outpatient clinic	1	(1)
	Mix	12	(11)

Table 1 (continued): Characteristics of studies on advance care planning (ACP)

Study Characteristics (N=113)		n	(%)
Type of ACP in study[a]	Do-not-resuscitate Order (DNR)	52	(39)
	Do-not-hospitalize Order (DNH)	16	(12)
	Advance directive / Living Will /Durable Power of Attorney	45	(34)
	Complex advance care planning intervention	20	(15)
Number of patients in study	0-100	13	(12)
	101-500	35	(31)
	501-1000	16	(14)
	>1000	49	(43)

ACP: advance care planning; DNR: do-not-resuscitate order; DNH: do-not-hospitalize order

[a] In 16 studies more than one type of ACP was investigated

The effects of advance care planning

Table 2 presents an overview of the effects of different types of advance care planning on the most prevalent outcomes. It shows the number of studies in which ACP was associated with a decrease or an increase in certain outcomes, the number of studies in which no significant association was found, and the number of studies that showed mixed results.

Studies on DNR orders (52 studies) mainly pertained to life-sustaining treatments (21 studies) and hospitalization and hospital length of stay (14 studies). Relatively few studies reported on the outcome of cardiopulmonary resuscitation (5 studies). Most studies on the effects of DNR orders showed that these were associated with a decreased use of cardiopulmonary resuscitation (4 of 5 studies) and an increased use of hospice and palliative care (6 out of 6 studies). A majority of studies showed a decrease in life-sustaining treatments (12 of 21 studies).

Studies on DNH orders (16 studies) showed a decrease in hospitalization (8 of 9 studies), a decrease in life- sustaining treatments (3 of 3 studies) and an increase in hospice and/or palliative care (5 of 5 studies).

In all, 45 studies reported on advance directives. Life-sustaining treatment was the most frequently studied outcome in 22 studies. For a majority of studies, presence of advance directives was associated with an increase in hospice and palliative care. For other outcomes, the results were mixed.

Studies on complex ACP pertain to a range of outcomes and were associated with an increase in compliance with patients' end-of-life wishes (3 of 4 studies).

Table 2: Summary: the effects of advance care planning

Type of Advance Care Planning (N=113)	Outcomes	Decreased (number of studies)	Increased (number of studies)	Mixed results (number of studies)	No difference (number of studies)
DNR (n=52)	Cardiopulmonary resuscitation (CPR) (5)	4	-	-	1
	Life sustaining treatment (incl. CPR) (21)	12	3	4	2
	Hospice and / or palliative care (6)	-	6	-	-
	Hospitalization / length of stay (14)	8	4	-	2
	ICU admission / length of stay (8)	2	3	-	3
	Quality of life / satisfaction (4)	1	1	-	2
DNH (n=16)	Hospitalization / length of stay (9)	8	-	-	1
	Life sustaining treatment (3)	3	-	-	-
	Hospice and /or palliative care (5)	-	5	-	-
	Quality of life / satisfaction (1)	-	-	-	1
Advance directives / living will / DPOA (n=45)	Compliance with patients' end-of-life wishes (2)	-	-	-	2
	Life sustaining treatment (22)	10	-	1	11
	Hospice and / or palliative care (7)	-	5	-	2
	Hospitalization / length of stay (8)	2	1	-	5
	Quality of life / satisfaction (6)	-	-	1	5
	Patients' and families' symptoms (8)	3	-	1	4

Table 2 (continued): Summary: the effects of advance care planning

Type of Advance Care Planning (N=113)	Outcomes	Decreased (number of studies)	Increased (number of studies)	Mixed results (number of studies)	No difference (number of studies)
Complex ACP intervention (n=20)	Compliance with patients' end-of-life wishes (4)	-	3	-	1
	Life sustaining treatment (5)	3	-	2	-
	Hospice and / or palliative care (5)	-	2	3	-
	Hospitalization / length of stay (4)	3	-	1	-
	Quality of life / satisfaction (8)	-	4	-	4
	Patients' and families' symptoms (5)	2	-	-	3

CPR: cardiopulmonary resuscitation; ICU: intensive care unit; DNR: do-not-resuscitate orders, DNH: do not hospitalize orders; DPOA: durable power of attorney; ACP: advance care planning.

Do-not-resuscitate orders

A total of 52 papers concerned DNR orders (Table 3). (20-71) All had an observational design: 31 were classified as grade II studies, and 31 were performed in the hospital (of which 8 were performed in the ICU). A total of 18 studies were performed among nursing home residents, including 13 of the 30 largest studies (over 1000 patients). Studies on DNR orders assessed associations with the use of medical treatment, place of care and quality of care.

A total of 21 studies investigated the association between DNR orders and life-sustaining treatment: in 12 studies DNR orders were associated with a decrease in life-sustaining treatment. A total of 10 studies looked at different forms of cardiopulmonary support. Nine found that DNR orders were associated with a decreased use of different types of cardiopulmonary support (CPR, cardiac catheterization and medication), and one study reported no association with resuscitation or mechanical ventilation. For tube feeding (six studies) the results were mixed: two studies found a decrease, two an increase, and two reported no association between DNR orders and tube feeding. DNR orders were also associated with a decreased use of diagnostic tests (two studies). Four studies reported on the association between DNR orders and the use of haemodialysis, in three studies DNR orders were related to a decreased use of haemodialysis. Mixed results or no results were found for the use of blood transfusion, antibiotics, hydration and stroke care.

Six studies investigated the outcome hospice care: in all six, having a DNR order was associated with more frequent enrolment in hospice care.

Seven studies investigated hospitalization as an outcome. Hospitalization was reported to be less common for patients with a DNR order in six studies, whereas one study showed no difference. Hospital length of stay was investigated in seven studies, of which four showed that DNR orders were associated with an increased length of stay, two with a reduced length of stay, and one study showed no association. DNR orders were also associated with fewer hospital deaths (3 studies) but more deaths in the ICU (1 study). Two studies found that DNR orders were associated with a decrease in ICU admissions and two studies found no association. Length of stay in the ICU was increased in patients with a DNR order in three studies, whereas one study found no association.

Quality of care was an outcome in three studies, of which one showed DNR orders to be associated with lower quality of care. In one study DNR orders were associated with an increased quality of life.

Do-not-hospitalize orders

A total of sixteen studies (reported in 17 papers), almost all of them performed in nursing homes, investigated DNH orders (Table 4). (24, 32, 36, 40, 44, 48, 52, 56, 57, 61, 72-78) All studies were observational and 10 included over 1000 individuals. Seven studies were classified as grade II studies. Outcome measures pertained to place of care, medical treatment and satisfaction.

Nine studies investigated the outcome hospitalization. Eight studies found that patients in nursing homes with a DNH order were less often hospitalized than patients without a DNH order, whereas one study found no difference. One study found no association with hospital length of stay. Two of two studies found that DNH orders were associated with fewer hospital deaths.

Studies on the effects of DNH orders on medical treatment were scarce (only three studies). These studies reported that patients with a DNH order were less likely to receive tube feeding, antibiotics and surgery. Of the five studies that reported on the outcome of hospice care, all reported that DNH orders were associated with an increased use of hospice care.

Finally, one study reported no significant association between the presence of a DNH order and health care proxies decision-making satisfaction.

Advance directives including living wills and durable powers of attorney

A total of 45 studies (in 44 papers) assessed the effects of advance directives including living wills and durable powers of attorney (Table 5).(18, 28, 32, 37, 40, 50, 55, 57, 61, 70, 79-112) All these studies were observational, 21 of them included over 1000 individuals and were performed in a variety of settings. Of all 45 studies, 31 were graded as level II studies. Outcome measures studied were medical treatment, place of care, symptoms, and satisfaction.

Two studies found no association between presence of an advance directive and whether or not patients' wishes were followed. Overall, 22 studies reported on the association between advance directives and (withdrawal of) life-sustaining treatment. In 10 studies advance directives were associated with a decrease in the use of life-sustaining treatments, including five studies that reported a decreased use of tube feeding. One study found that the presence of a durable power of attorney was associated with an increase in invasive procedures (except for cardiac catheterization). Eleven studies, mainly performed in the hospital and intensive care setting, reported no differences in the use of life-sustaining treatment.

In five of seven studies, patients with advance directives were more frequently enrolled in hospice care and/or palliative care provision. Four of six studies found that advance directives were associated with an increase in the use of comfort plans.

Six studies reported on the association with in-hospital deaths: two studies reported a decrease in hospital deaths, two studies reported mixed results, and two reported no association. Three studies reported an increase in out-of-hospital deaths.

Six studies reported on the association between advance directives and patient and family satisfaction, quality of life, or quality of death and dying. One study reported mixed results for quality of death and dying, five other studies reported no difference in quality of life, quality of care, and patient and surrogate satisfaction.

Eight studies investigated patient and family symptoms, with mixed results. Advance directives were associated with a decrease in family concerns or stress and learned helplessness (three studies). One study found mixed results for 'depression'. No difference was reported in symptom management, symptoms in the last week of life, caregiver strain, patient anxiety, patient depression, and several aspects of patient's physical and social functioning (four studies).

Complex advance care planning interventions

A total of 20 studies reported on the effects of complex ACP interventions (Table 6). (17, 79, 113-130) This type of ACP was the only one that was tested in an experimental design, in six studies. Two of 14 observational studies included over 1000 individuals. Different interventions were investigated, such as the Let Me Decide advance directive program, the Respecting Choices Programme, the Physician Orders for Life-Sustaining Treatment (POLST) Programme, the Let Me Talk Programme, the Making Advance Care Planning a Priority (MAPP) Programme and several self-developed interventions such as conversations with a trained care planning mediator, a social work intervention, an advance directive tool, and a pathway tool for present and advance directives. Outcome measures in these studies included compliance with patients' end-of-life wishes, medical treatment, hospice and palliative care, place of care, satisfaction and symptoms.

Four studies investigated the effect on compliance with patients' end-of-life wishes; three reported increased compliance and one reported no significant effect. Five studies investigated the use of life-sustaining treatment. Two found mixed results, one reported a decrease in resuscitation, one a decrease in dialysis at the end of life, and one a decrease in emergency calls to ambulance services. Five studies reported on the effects on palliative care and hospice care: in two studies ACP interventions were associated with an increase of hospice use and use of palliative pathways, three other studies found mixed results.

Three out of three studies reported a decrease in hospitalizations as a result of a complex advance care planning intervention, one study reported a decrease in ICU admissions. In two studies the association with hospital length of stay was investigated: one study reported a decrease and one study reported no difference in hospital length of stay. Six studies investigated the place of death. Three studies reported a decrease of in-hospital deaths, one study reported a decrease in ICU deaths, and two studies reported an increase in at-home deaths.

Eight studies reported on the association between complex ACP interventions and satisfaction and quality of life. Four studies reported an increase in satisfaction or quality of life, four studies did not find any difference for satisfaction. The effects of complex ACP interventions on symptoms (5 studies) such as anxiety and depression, were mixed. Two studies reported a decrease in family existential concerns, depression and anxiety. Three other studies did not find any difference in symptoms such as depression, anxiety, psychological distress, or pain and shortness of breath.

Table 3: Information on studies investigating do-not-resuscitate orders

Authors and reference no.	Year of publication	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes Decreased (use of):	 Increased (use of):	 No difference (in the use of):
Gozalo et al. (61)	2011	NH	IIA	Medicare decedents with advanced cognitive and functional impairment	474,829	Hospitalisation[c]		
Gozalo and Miller (48)	2007	NH	IIA	Nursing home residents who died in the years 1995-1997	183,742	Hospitalisation	Hospice care	
Stephens et al. (65)	2012	NH	IIA	Residents with cognitive impairment	132,753			Emergency department use
Baker et al. (41)	2004	HO	IIA	Medicare patients discharged alive after hospitalisation	83,445			Hospital length of stay Readmission rate to hospital
Scarborough et al. (66)	2012	HO	IIA	Patients > 65 years undergoing emergency operation	25,558	Reoperation		Post-operative length of stay Intraoperative transfusion
Teno et al. (53)	2011	NH	IIA	Nursing home residents	15,784	Hospitalisation		

Table 3 (continued): Information on studies investigating do-not-resuscitate orders

Authors and reference no.	Year of publication	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes Decreased (use of):	 Increased (use of):	 No difference (in the use of):
Higgins et al. (39)	2003	ICU	IIA	Critically ill medical, surgical and trauma patients	10,900	Days in hospital		
Lu. and Johantgen (56)	2011	NH	IIA	Newly admitted, older nursing home residents	10,023		Hospice care	
Miller et al. (24)	2001	NH	IIA	Nursing home residents who enrolled in hospice between 1992 and 1996 and who died before 1998	9809	Hospitalisation		
Fissel et al. (49)	2005	MIX	IIA	Haemodialysis patients	8615		Withdrawal from haemodialysis	
Jackson et al. (38)	2004	HO	IIA	Patients with acute myocardial infarction	4621	Aspirins B-blockers ACE-inhibitors		

Table 3 (continued): Information on studies investigating do-not-resuscitate orders

Authors and reference no.	Year of publication	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
						Decreased (use of):	Increased (use of):	No difference (in the use of):
Chen et al. (63)	2008	HO	IIA	Patients with acute heart failure	4537	Assessment of left ventricular function Renin-angiotensin system blockade Anticoagulation non-pharmacological interventions Quality assurance measure for acute heart failure.		
Reed et al. (35)	2003	HO	IIA	Mobility impaired hospitalised adults	2771		Pressure ulcers	
Casarett et al. (30)	2001	MIX	IIA	Patients enrolled in a urban, non-profit hospice program	1691	Withdrawal from hospice		
McNeill et al. (69)	2012	HO	IIA	General medical inpatients	1681		Hospital length of stay	

Table 3 (continued): Information on studies investigating do-not-resuscitate orders

Authors and reference no.	Year of publication	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
						Decreased (use of):	Increased (use of):	No difference (in the use of):
Zweig et al. (42)	2004	NH	IIA	Nursing home residents with a lower respiratory infection	1031	Hospitalisation		
Zahuranec et al. (43)	2007	HO	IIA	Patients with intracerebral haemorrhage	270	Discharge disposition: home or rehabilitation hospital		
Saczynski et al. (67)	2012	HO	IIB	Patients hospitalised with acute myocardial infarction	4182	In-hospital medications Intervention procedures		
Huang et al. (60)	2009	ICU	IIB	Terminally ill patients at a surgical ICU	1149		Death in ICU	
Cook et al. (29)	2003	ICU	IIB	Critically ill patients receiving mechanical ventilation	851	Mechanical ventilation		

Table 3 (continued): Information on studies investigating do-not-resuscitate orders

Authors and reference no.	Year of publication	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
						Decreased (use of):	Increased (use of):	No difference (in the use of):
Sinuff et al. (34)	2004	ICU	IIB	Mechanically ventilated patients	765	Inotropic drugs Vasopressors Dialysis Mechanical ventilation Hospital length of stay		ICU length of stay
Mohammed et al. (45)	2006	HO	IIB	Acute stroke patients	702	Aspirins Care on a stroke unit or by a stroke team Time in a rehabilitation ward	Speech therapy	
Cohen et al. (70)	2012	HO	IIB	Patients with consultation for Medical Intensive Care Unit admission	572	Admission to a Medical Intensive Care Unit.		
Levy et al. (46)	2006	NH	IIB	Residents with a urinary tract infection	564			Practitioner assessment and/or hospitalization

Table 3 (continued): Information on studies investigating do-not-resuscitate orders

Authors and reference no.	Year of publication	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
						Decreased (use of):	Increased (use of):	No difference (in the use of):
Bacchetta et al. (51)	2006	ICU	IIB	Surgical ICU patients who were given a DNR order from May 1 1991 to May 31 1998	410		ICU length of stay	
Maciejewski et al. (55)	2012	HO	IIB	Patients with advanced cancer	345			Mechanical ventilation or resuscitation
Chang et al. (64)	2010	ICU	IIB	Critically ill patients	202	Withdrawal of therapy Vasopressors Cardiac massage Pacemaker Cardiopulmonary Resuscitation Mechanical ventilation Supplemental oxygen	ICU length of stay	Blood transfusion Intravenous hydration Haemodialysis Endotracheal intubation Total parenteral nutrition Tube feeding
Han et al. (47)	2007	HO	IIB	Elderly patients with acute coronary symptoms	201	Cardiac catheterization		

Table 3 (continued): Information on studies investigating do-not-resuscitate orders

Authors and reference no.	Year of publication	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes Decreased (use of):	 Increased (use of):	 No difference (in the use of):
Moroney et al. (23)	2001	HO	IIB	Patients with invasive pneumonia	146			ICU admission
Keller et al. (26)	2001	NH	IIB	Residents >60 years	134			Examination by an eye care specialist
Keenan and Kish (27)	2000	ICU	IIB	Cancer patients in the surgical ICU	23	Laboratory tests Radiographs		
Teno et al. (20)	2002	NH	IIIA	Residents with severe cognitive impairment	385,741	Tube feeding		
Lepore et al. (57)	2011	NH	IIIA	Nursing home residents	288,202		Hospice care	
Mitchell et al. (37)	2003a	NH	IIIA	Residents with advanced cognitive impairment	186,835	Tube feeding		
Ahronheim et al. (32)	2011	NH	IIIA	Residents with cognitive impairment	57,029		Tube feeding	
Zheng et al. (52)	2011	HO	IIIA	Long-term care residents	49,048	In-hospital death	Hospice	

Table 3 (continued): Information on studies investigating do-not-resuscitate orders

Authors and reference no.	Year of publication	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
						Decreased (use of):	Increased (use of):	No difference (in the use of):
Buchanan et al. (40)	2004	NH	IIIA	Residents with an end-stage disease	18,211		Hospice care	
Gessert et al. (28)	2000	NH	IIIA	Residents with cognitive impairment	4997			Tube feeding
Kazaure et al. (58)	2011	HO	IIIA	Surgical patients	8256		Total time in operating room Hospital length of stay Days from operation to discharge	
Temkin-Greener and Mukamel (21)	2002	COM	IIIA	Frail, nursing home eligible people	2263	Death in hospital		
Reeves et al. (68)	2012	HO	IIIA	Veterans with acute ischaemic stroke	3965	Early ambulation		13 quality indicators for stroke care (in multivariate analysis)

Table 3 (continued): Information on studies investigating do-not-resuscitate orders

Authors and reference no.	Year of publication	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
						Decreased (use of):	Increased (use of):	No difference (in the use of):
Rector et al. (44)	2005	NH	IIIA	EverCare enrolees admitted to intensive service days or a hospital for suspected pneumonia in 2002	1009	Hospitalisation		
Marrie et al. (25)	2002	HO	IIIB	Patients with community-acquired pneumonia	1339		Antibiotics Hospital length of stay	
Huang et al. (59)	2010	ICU	IIIB	Patients admitted to a surgical ICU	873	Supplemental oxygen Inotropic drugs Haemodialysis Laboratory tests Radiographs Blood transfusion Sedatives Analgesics	Tube feeding ICU length of stay	Mechanical ventilation Antibiotics Neuromuscular blocking drugs Mechanical circulatory support
Becker et al. (31)	2003	NH	IIIB	Patients with a cardiac arrest	392	Cardiopulmonary Resuscitation		

Table 3 (continued): Information on studies investigating do-not-resuscitate orders

Authors and reference no.	Year of publication	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
						Decreased (use of):	Increased (use of):	No difference (in the use of):
Finlay et al. (62)	2008	HO	IIIB	Patients that died of cancer who received care from a VA medical centre in the last month of life	262		Quality of life (patient)	
Martinez-Selles et al. (54)	2010	HO	IIIB	Cardiac patients	198	Admission to critical care unit	Hospital length of stay	
Dobbins (50)	2007	HO	IIIB	Patients >65 years who died in hospital	160	Cardiopulmonary Resuscitation		
Pekmezaris et al. (36)	2004	NH	IIIB	Deceased nursing home residents	100	Death in hospital		
Sulmasy and McIlvane (22)	2002	HO	IIIB	Seriously ill medical inpatients	84			Quality of care / satisfaction
Sulmasy et al. (71)	2002	HO	IIIB	Medical inpatients	61	Quality of care / satisfaction		

Table 3 (continued): Information on studies investigating do-not-resuscitate orders

Authors and reference no.	Year of publication	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
						Decreased (use of):	Increased (use of):	No difference (in the use of):
Tanvetyanon and Leighton (33)	2003	HO	IIIB	Patients with congestive heart failure or cancer	58	Cardiopulmonary Resuscitation		Mechanical ventilation, vasopressors, ICU use

ACE: angiotensin-converting enzyme; DNR: do-not-resuscitate; VA: Veterans's Affairs.

[a] Setting: COM=community, NH=nursing home, HO=hospital, ICU=intensive care unit, MIX=a mixture of settings

[b] See Box 2

[c] Defined as 'burdensome transitions', which includes hospitalizations in the last 3 days of life, a lack of continuity in nursing homes after hospitalization in the last 90 days of life, or multiple hospitalizations in the last 90 days of life.

Table 4: Do-not-hospitalize orders

Authors and reference no.	Year of publication	Setting[a]	Grade of evidence[b]	Patient population	Number of patients studied	Outcomes		
						Decreased (use of):	Increased (use of):	No difference (in the use of):
Gozalo et al. (61)	2011	NH	IIA	Medicare decedents with advanced cognitive and functional impairment who were nursing home residents 102 days before death	474,829	Hospitalization[c]	Hospice care	
Gozalo and Miller (48)	2007	NH	IIA	Nursing home residents who died in the years 1995-1997	183,742	Hospitalization		

Table 4 (continued): Do-not-hospitalize orders

Authors and reference no.	Year of publication	Setting[a]	Grade of evidence[b]	Patient population	Number of patients studied	Outcomes		
						Decreased (use of):	Increased (use of):	No difference (in the use of):
Lu and Johantgen (56)	2010	NH	IIA	Newly admitted, older nursing home residents	10,023		Hospice care	
Miller et al. (24)	2001	NH	IIA	Nursing home residents who enrolled in hospice between 1992 and 1996 and who died before 1998	9809	Hospitalization		
Dobalian (75)	2004	NH	IIA	Nursing home residents	5899	Hospitalization		
Givens et al. (74) (73)	2009, 2012	NH	IIB	Residents with advanced dementia	323	Hospital transfers		Decision-making satisfaction
Chen et al. (77)	2006	NH	IIB	Patients with end-stage dementia	240	Antibiotics		
Lepore et al. (57)	2011	NH	IIIA	Nursing home residents	288,202		Hospice care	
Ahronheim et al. (32)	2001	NH	IIIA	Residents with cognitive impairment	57,029	Tube feeding		
Zheng et al. (52)	2011	HO	IIIA	Long-term care residents	49,048	In-hospital death	Hospice care	
Buchanan et al. (40)	2004	NH	IIIA	Residents with an end-stage disease	18,211		Hospice care	

Table 4 (continued): Do-not-hospitalize orders

Authors and reference no.	Year of publication	Setting[a]	Grade of evidence[b]	Patient population	Number of patients studied	Outcomes Decreased (use of):	 Increased (use of):	 No difference (in the use of):
Rector et al. (44)	2005	NH	IIIA	EverCare enrolees admitted to intensive service days or a hospital for suspected pneumonia in 2002	1009	Hospitalization		
Maust et al. (72)	2008	NH	IIIB	Residents with advanced dementia	123	Hospitalization and/or surgery		
Anderson et al. (78)	2006	NH	IIIB	Peritoneal dialysis patients	109			Hospitalization Hospital length of stay
Pekmezaris et al. (36)	2004	NH	IIIB	Deceased nursing home residents	100	In-hospital death		
Cohen-Mansfield and Lipson (76)	2006	NH	IIIB	Nursing home residents	52	Hospitalization		

[a] Setting: NH= nursing home, HO=hospital

[b] See Box 2

[c] Defined as ‘burdensome transitions’, which includes hospitalizations in the last 3 days of life, a lack of continuity in nursing homes after hospitalization in the last 90 days of life, or multiple hospitalizations in the last 90 days of life.

Table 5: Written advance directives

First author and reference no.	Year of publi-cation	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes Decreased (use of):	 Increased (use of):	 No difference (in the use of):
Gozalo et al. (61)	2011	NH	IIA	Medicare decedents with advanced cognitive and functional impairment who were nursing home residents 102 days before death	474,829	Hospitalization[c]		
Radcliff et al. (92)	2007	HO	IIA	Patients with acute myocardial infarction	147,475	Aspirin Beta-blocker Reperfusion		
Greiner et al. (89)	2003	MIX	IIA	Individuals >15 years who died in 1993 of non-traumatic causes	11,291		Hospice care	
Levy et al. (109)	2012	NH	IIA	Veterans residing in community living centres	7408		Death in a community living centre	
Jeurkar et al. (112)	2012	MIX	IIA	Hospice patients with cancer	5837		Death at home	
Silveira et al. (18)	2010	MIX	IIA	Persons > 60 years who died between 2000 and 2006	3746	In-hospital death[d] Receipt of all care possible	Comfort plans[e]	Limited care Comfort plans[d] In-hospital death[e]
Kelley et al. (110)	2011	MIX	IIA	People aged 67 years and older who died between 2000 and 2006	3539			In-hospital death

Table 5 (continued): Written advance directives

First author and reference no.	Year of publi-cation	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes Decreased (use of):	 Increased (use of):	 No difference (in the use of):
Nicholas et al. (107)	2011	MIX	IIA	Medicare beneficiaries	3302	In-hospital death [f]	Hospice care [f]	In-hospital death [g] Life-sustaining treatments
Mubareka et al. (94)	2007	NH	IIA	Residents prescribed antimicrobial therapy for presumed lower respiratory tract infection	1702			Diagnostic tests Radiographs Oxymetry White blood cell count
Teno et al. (91)	2007	MIX	IIA	Bereaved family members	1587	Respirator Tube feeding Concerns with communication Concerns with what to expect Death in ICU		Respectful treatment Emotional support Pain support Dyspnea support Emotional support Quality of care Hospice length of stay Compliance with end-of-life wishes
Rose et al. (85)	2004	HO	IIA	Older and middle-aged patients with cancer	1416		Readmission to hospital	
Tilden et al. (83)	2004	COM	IIA	Caregivers of decedents aged > 65 years who died a natural death in the community setting	1189			Caregiver strain

Table 5 (continued): Written advance directives

First author and reference no.	Year of publi-cation	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes Decreased (use of):	 Increased (use of):	 No difference (in the use of):
Halpern et al. (95)	2011	ICU	IIA	Critically ill cancer patients	1121			ICU stay Hospital length of stay Mechanical ventilation Mechanical ventilation upon discharge Vasopressors in ICU Intubation Intubation in ICU Tracheostomy Days in ICU to tracheostomy Haemodialysis Endoscopy PEG/PEJ Chemotherapy Cardiopulmonary Resuscitation Withdrawal of life-sustaining treatment
Mitchell et al. (86)	2003b	NH	IIA	Residents >65 years with advanced cognitive impairment	1057	Tube feeding		
Yoo et al. (104)	2012	HO	IIB	Community-dwelling, critically ill older adults	1673		Hospice discharges	

Table 5 (continued): Written advance directives

First author and reference no.	Year of publi-cation	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
						Decreased (use of):	Increased (use of):	No difference (in the use of):
Kelley et al. (88)	2006	ICU	Study 1 IIB	Chronically critically ill, mechanically ventilated patients	530	In-hospital death		Length of mechanical ventilation Mechanical ventilation ICU stay Hospital length of stay Being terminally weaned
			Study 2 IIB		598			In-hospital death [i] Length of mechanical ventilation Mechanical ventilation ICU stay Hospital length of stay Being terminally weaned
Cohen et al. (70)	2012	HO	IIB	Patients who had consultation for Medical Intensive Care Unit admission	572	Admission to a Medical Intensive Care Unit		
Degenholtz et al. (90)	2004	COM	IIB	People > 70 years living in the community	539	In-hospital death Receipt of all life-sustaining medical treatment	Comfort plans, Treatments withheld	
Jones et al. (111)	2012	HO	IIB	Patients who received a medical emergency team call over 1 month	518	Discharge home		

Table 5 (continued): Written advance directives

First author and reference no.	Year of publi-cation	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
						Decreased (use of):	Increased (use of):	No difference (in the use of):
Sullivan et al. (106)	2012	ICU	IIB	Patients admitted to an ICU in a large university hospital	499	Learned helplessness [m]		
Glavan et al. (96)	2008	ICU	IIB	Patients who died in the ICU or within 24 h of being transferred from an ICU	365		Quality of dying and death [g]	Quality of dying and death [f]
Franklin et al. (98)	2011	HO	IIB	Deceased trauma patients	347	Operations	Withdrawal of care Comfort plans	
Maciejewski et al. (55)	2012	HO	IIB	Patients with advanced cancer	345	Mechanical ventilation or resuscitation		
Ganti et al. (97)	2007	HO	IIB	Patients undergoing their first haematopoietic stem-cell transplantation	343			Hospital length of stay

Table 5 (continued): Written advance directives

First author and reference no.	Year of publi-cation	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
						Decreased (use of):	Increased (use of):	No difference (in the use of):
Loberiza et al. (108)	2011	HO	IIB	Patients with haematologic malignancies	293			Anxiety Depression Quality of life Physical composite score Mental composite score Physical functioning Role limitation due to physical problems Bodily pain Social functioning General mental health Role limitation due to emotional problems Vitality General health perception
Swartz et al. (84)	2004	ICU	IIB	Patients with severe acute renal failure	383			Withdrawal of life-sustaining treatment
Cesta et al. (101)	2009	ICU	IIB	Patients with cancer who died in the ICU	267			ICU length of stay Withdrawal of life-sustaining therapy

Table 5 (continued): Written advance directives

First author and reference no.	Year of publi-cation	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
						Decreased (use of):	Increased (use of):	No difference (in the use of):
Cosgriff et al. (99)	2007	COM	IIB	Community-dwelling persons aged ≥ 65 years with advanced disease who died during a study which prospectively assessed treatment preferences.	118			Care trajectory (incl. life sustaining treatment)
Meier et al. (87)	2001	HO	IIB	Hospitalized patients with advanced dementia	99			Tube feeding
Pautex et al. (93)	2008	HO	IIB	Patients with advanced cancer	53	Depression[h]		Patient satisfaction Surrogates satisfaction Depression[i] Anxiety Total symptom burden
Lepore et al. (57)	2011	NH	IIIA	Nursing home residents	288,202		Hospice care	

Table 5 (continued): Written advance directives

First author and reference no.	Year of publi-cation	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
						Decreased (use of):	Increased (use of):	No difference (in the use of):
Mitchell et al. (37)	2003a	NH	IIIA	Residents with advanced cognitive impairment	186,835	Tube feeding		
Ahronheim et al. (32)	2001	NH	IIIA	Residents with cognitive impairment	57,029	Tube feeding		
Buchanan et al. (40)	2004	NH	IIIA	Residents with an end-stage disease	18,211		Hospice care	
Gessert et al. (28)	2000	NH	IIIA	Residents with cognitive impairment	4997	Tube feeding		
Chen et al. (100)	2008	ICU	IIIB	Critically ill patients	2211			Intubation, Hospital length of stay ICU length of stay
Vandervoort et al. (105)	2012	NH	IIIB	Residents with dementia	764			Palliative care provision Mildness of death Quality of life Place of death Symptoms present in last week of life

Table 5 (continued): Written advance directives

First author and reference no.	Year of publi-cation	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
						Decreased (use of):	Increased (use of):	No difference (in the use of):
Wallace et al. (80)	2001	ICU	IIIB	Critically ill cancer patients	270	ICU length of stay		Mechanical ventilation Inotropic support PA catheterization Cardiopulmonary Resuscitation Renal dialysis
Becker et al. (103)	2007	HO	IIIB	Patients who died in hospital	226		Comfort plans	
Bernal et al. (102)	2007	HO	IIIB	Patients who died in hospital	165			Compliance with end-of-life wishes
Dobbins (50)	2007	HO	IIIB	Patients >65 years who died in hospital	160		Any invasive procedure [j] (except cardiac catheter-ization)	Life-sustaining treatment [k] Comfort plans [l]
Volicer et al. (81)	2003	MIX	IIIB	Dementia patients that died in different care settings	156	Hospital length of stay	Death in nursing home	Satisfaction Symptom management
Watch et al.(79)	2005	ICU	IIIB	Trauma patients >55 years	64			Withdrawal of life-sustaining therapy

Table 5 (continued): Written advance directives

First author and reference no.	Year of publi-cation	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes Decreased (use of):	 Increased (use of):	 No difference (in the use of):
Tilden et al. (82)	2001	HO	IIIB	Deceased patients whose death followed withdrawal of life-sustaining treatment	51	Family stress		

PEG/PEJ: percutaneous endoscopic gastrostomy/percutaneous endoscopic jejunostomy; PAC: pulmonary artery catherterisation.

[a] Setting: COM=community, NH=nursing home, HO=hospital, ICU=intensive care unit, MIX=mixture of different settings.

[b] See Box 2

[c] Concerns 'burdensome transitions', which includes hospitalizations in the last 3 days of life, a lack of continuity in nursing homes after hospitalization in the last 90 days of life, or multiple hospitalizations in the last 90 days of life.

[d] For patients with a durable power of attorney

[e] For patients with a living will

[f] For regions with medium and high rates of Medicare expenditures

[g] For regions with low rates of Medicare expenditures

[h] Depression one week after inclusion

[i] Depression on the third week after inclusion

[j] For informal durable powers of attorney for health care

[k] For formal advance directives

[l] For formal or informal advance directives

[m] Concerns presence of an advance directive or a do-not-resuscitate order, significant only in the univariate analysis

Table 6: Complex advance care planning interventions

Authors and references	Year of public-cation	Intervention	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
							Decreased (use of):	**Increased (use of):**	**No difference (in the use of):**
Detering et al. (17)	2010	Respecting Choices	HO	IA	Hospitalized patients, > 80 years	309	Impact of events scale score Depression Anxiety Death in ICU	Compliance with end of life wishes Satisfaction with quality of death Patients' satisfaction	
Molloy et al. (119)	2000	Let Me Decide	NH	IB	Nursing home residents	1292	Hospitalization Hospital length of stay		Satisfaction
Tierney et al. (114)	2001	AD discussions	COM	1B	Elderly, chronically ill patients	686			Satisfaction with physician
Kirchhoff et al. (130)	2012	Patient centered advance care planning (PC-ACP)	MIX	1B	Patients with congestive heart failure or end-stage renal disease	313	Dialysis at the end of life		CPR wishes met
Morrison et al. (118)	2005	Self -developed	NH	IB	Long-term care residents	139		Compliance with end-of-life wishes	

Table 6 (continued): Complex advance care planning interventions

Authors and references	Year of public-cation	Intervention	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
							Decreased (use of):	Increased (use of):	No difference (in the use of):
Jones et al. (122)	2011	Self-developed	MIX	IB	Patients with advanced cancer	77			Satisfaction with treatment Happiness with communication Anxiety Depression
Hickman et al. (125)	2010	POLST	NH	IIA	Residents > 65 years with a minimum 60-day stay	1711	Life-sustaining treatment	Hospice care	Antibiotics Any pain medication Any non-opioid pain medication Daily morphine equivalent, Any treatments for shortness of breath Pain present Number of days of pain Shortness of breath present Number of days shortness of breath
Chan and Pang (128)	2010	Let me Talk	NH	IIA	Frail nursing home residents	121	Existential concerns Physical discomfort	Quality of life	

Table 6 (continued): Complex advance care planning interventions

Authors and references	Year of public-cation	Intervention	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
							Decreased (use of):	**Increased (use of):**	**No difference (in the use of):**
Hammes et al. (126)	2012	POLST[c]	COM	IIB	Deceased adults	400	Death in hospital (instead of nursing home)		
Sittisombut et al. (115)	2008	Self-developed	HO	IIB	Patients > 40 years, admitted to hospital	376	In-hospital death Cardiopulmonary resuscitation		
Wright et al. (113)	2008	End-of-life discussions	OPC	IIB	Patients with advanced cancer	332	Admission to ICU Mechanical ventilation Resuscitation	Outpatient hospice > 1 week	Chemotherapy Tube feeding Outpatient Hospice used Major depressive disorder, Generalized anxiety disorder Panic disorder Posttraumatic stress disorder Any mental disorder McGill psychological subscale Any psychological distress

Table 6 (continued): Complex advance care planning interventions

Authors and references	Year of public-cation	Intervention	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
							Decreased (use of):	Increased (use of):	No difference (in the use of):
Kiely et al. (121)	2012	AD discussions	NH	IIB	Residents >60 years with dementia	323		Satisfaction	
Schellinger et al. (116)	2011	Respecting Choices	MIX	IIB	Heart failure patients	286		Hospice care	Hospice length of stay
Schamp and Tenkku (117)	2006	Self-developed	COM	IIB	Frail, elderly patients	160		Compliance with end-of-life wishes Palliation pathway Death at home	
Levy et al. (120)	2008	MAPP[d]	NH	IIB	Nursing home residents	72	In-hospital death Hospitalization	Palliative care referrals	Hospital length of stay Hospice referral Days hospice Days palliative care
Caplan et al. (129)	2006	Let Me Decide	NH	IIB	Nursing home residents	45	Hospitalization Emergency calls to ambulance service		
Hughes et al. (123)	2010	Not specified ACP	COM	IIIA	General practices	2096		Death at home	
Ho et al. (124)	2000	Self-developed	COM	IIIB	Persons with HIV/AIDS	210			Satisfaction with care

Table 6 (continued): Complex advance care planning interventions

Authors and references	Year of public-cation	Intervention	Setting[a]	Grade of evidence[b]	Patient population	No. of patients studied	Outcomes		
							Decreased (use of):	Increased (use of):	No difference (in the use of):
Engel et al. (127)	2006	Advance directive discussions	NH	IIIB	Residents 65 years, with advanced dementia	148		Satisfaction with care	
Watch et al. (79)	2005	Family discussions	ICU	IIIB	Trauma patients >55 years	64		Withdrawal of life-sustaining therapy	

AD: advance directive; POLST: Physician Orders for Life-Sustaining Treatment; CPR: cardiopulmonary resuscitation; MAPP: Making Advance Care Planning a Priority

[a] Setting: COM=community, NH=nursing home, HO=hospital, ICU=intensive care unit, OPC=outpatient clinic, MIX=mixture of different settings.

[b] See Box 2

Discussion

Research on the outcome of ACP has mainly been performed in the USA, and in institutional settings such as nursing homes, hospitals and ICUs. Implementation of the Patient Self-Determination Act in 1990 might explain the large number of studies performed in the USA. Most studies in the present review had an observational design, with (sometimes) large numbers of patients, and most frequently analyzed written documents or agreements. Several experimental studies, of which only a few were randomized controlled trials, assessed the effects of more complex ACP interventions. The objective of advance care planning is to enable patients to make treatment decisions in advance in an attempt to provide care consistent with their goals when they are no longer capable of making such decisions.(131) From this perspective it is noteworthy that only a few studies assessed whether care as received was congruent with end-of-life wishes as written down in an advanced care plan. More common outcome measures were related to medical interventions, place of care and type of care.

Studies on the outcomes of DNR orders were not limited to the question of whether or not patients with a cardiac arrest are less likely to be resuscitated in the presence of a DNR order. Whereas DNR orders were found to reduce the use of cardiopulmonary support measures, they also tended to reduce the number of hospitalizations and to increase the use of hospice care. Evidence concerning the association of DNR orders with other interventions is not convincing. It should be noted that the outcome of DNR orders was only studied in observational studies, albeit with (in some cases) very large numbers of patients. This means that it remains unclear whether there is a causal relationship between DNR orders and the place and type of medical care. DNR orders are probably more often written down for the most severely ill patients, for whom the goals of medical care might also have been refocused without an explicit DNR order. Moreover, patients who had a clear preference for comfort care, instead of life-sustaining treatment, were probably overrepresented among patients with DNR orders. Finally, DNR orders may not in all cases have been the result of an ACP process in which the patient explicitly expressed his or her wishes: DNR orders may be established by physicians without involving the patient, either or not in consultation with the patient's family.

DNH orders have almost invariably been shown to be related to a reduced number of hospitalizations and an increased use of hospice care. Studies on DNH orders have been mainly performed among nursing home residents. Other outcomes, such as satisfaction or quality of care, have rarely been studied. Inferences about a causal relationship between DNH orders and care outcomes are also difficult to make due to the observational design of the studies. In nursing homes, DNH orders may often be the result of a more extensive process of discussing and planning future care. As such, they may represent an effective element of such a process.

Research on the outcomes of ACP most commonly focuses on written advance directives. All the studies included in this review had an observational design and were performed in various settings. We found considerable variance in the types of outcomes studied, with mostly mixed results. Advance directives tend to be related to an increased frequency of out-of-hospital care that is aimed at increasing the patient's comfort rather than prolongation of life. The latter is expressed in a reduced frequency of the use of tube feeding, but for other medical interventions no associations or mixed results were found. Most studies that did not find associations with medical treatment were performed in the hospital setting, mainly in ICUs. This finding supports the idea of Degenholtz et al. who state that the fact that people are hospitalized suggests that they, or their families, want some kind of medical intervention and that *"a living will may not be enough to outweigh the hospital's technological imperative".* (90) Furthermore, advance directives were not found to be clearly associated with symptom burden, quality of life/quality of dying, or satisfaction with care. However, we did not assess the content of the written advance directives; this implies that (in addition to the fact that all studies had an observational design) it is difficult to draw firm conclusions about their effect. Nevertheless, whereas the present review suggests that advance directives may contribute (to some extent) to reducing overtreatment at the end of life, it seems unlikely that they have a substantial impact on patient-centered end-of-life care and satisfaction with care.

Nowadays, advance care planning is seen as a process of communication between patients and professional caregivers that may include (but is not limited to) the completion of written agreements and advance directives.(132) The effects of such complex interventions were addressed in 20 of the included studies, and they were the only type of advance care planning that was investigated in experimental research. Several interventions, such as the Respecting Choices Programme, the Let Me Decide Programme, advance directive discussions, and self- developed interventions were studied in randomized controlled trials. The Respecting Choices Programme showed an increase in compliance with end-of-life wishes and satisfaction with quality of death; this program involves a coordinated approach to ACP whereby trained non-medical facilitators, in collaboration with treating physicians, assist patients and their families to reflect on the patient's goals, values and beliefs, and to discuss and document their future choices about health care. The Let Me Decide advance directive program includes educating staff in local hospitals and nursing homes, residents, and families about advance directives and offering competent residents or next-of-kin of mentally incompetent residents an advance directive that provides a range of health care choices for life-threatening illness, cardiac arrest, and nutrition.

Complex ACP interventions were found to result in an increased frequency of out-of-hospital and out-of-ICU care, and in increased compliance with patients' end-of-life wishes and satisfaction with care. We did not find clear results with respect to medical care, except for a tendency towards an increased use of hospice and palliative care.

In a small majority of the studies, psychosocial measures were positively affected by ACP. The absence of adverse effects of ACP on psychosocial outcomes is noteworthy. Patients or families who participate in advance care planning did not report more stress, anxiety or depression compared to patients or families who did not participate in advance care planning.

Study limitations

This review has several limitations. First, it was difficult to find an adequate search strategy to identify papers. Different types of ACP have been studied in different settings, including a broad range of outcomes. Checking the references of included papers resulted in a substantial number of additional papers, which suggests that our search strategy may not have captured all relevant studies. Furthermore, our search terminology may best fit the American situation and can be different in other countries. For example, the terminology used in the United Kingdom includes advanced wishes, advance decisions to refuse treatment, and appointment of a proxy health care decision-maker. Do-not-attempt cardiopulmonary resuscitation (DNA CPR) may also be part of ACP if based on patients' wishes".(133) An additional search with this terminology however did not result in any extra papers that met our criteria.

Second, we did not include studies in which ACP was one component of a larger intervention, for instance palliative care consultation. Extensive palliative care interventions that include ACP are known to have positive effects on patient satisfaction, patient knowledge and psychological adjustments.(134)

Third, we did not assess specific details of the different types of ACP addressed in different studies, which hampers drawing inferences about which aspects of ACP may be most effective. In addition, due to the broad range of different outcomes, we were not able to calculate effect sizes.

We conclude that there is some evidence that ACP positively impacts the quality of end-of-life care. Do-not-resuscitate orders were found to reduce the use of cardiopulmonary support measures, to reduce hospitalizations and to increase the use of hospice care. Do-not-hospitalize orders have almost invariably been shown to be related to a reduced number of hospitalizations and an increased use of hospice care. The effects of advance directives seem more diverse but they tend to be related to an increased frequency of out-of-hospital care that is aimed at increasing the patient's comfort instead of prolongation of life. Extensive ACP interventions may be more effective than written documents alone. They were found to result in an increased frequency of out-of-hospital and out-of-ICU care, and in increased compliance with patient wishes and satisfaction with care. However, research on the outcome of ACP is very diverse. More studies are needed with an experimental design, outside the USA, in different settings, including the community. Outcome measures for such studies should preferably be standardized and focus on the experiences of patients and their families.

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CHAPTER 12

General discussion

Discussion

This chapter describes the main findings of this thesis and highlights important considerations regarding the role of palliative care teams (PCTs) in care for patients with advanced cancer in Dutch hospitals. We found that the majority of Dutch hospitals have a PCT. Other hospitals are in the process of setting up a PCT. PCT consultation is provided in less than one percent of all hospital admissions. PCTs in hospitals are mainly consulted for patients with a life expectancy of less than three months without options for curative treatment, who are unexpectedly hospitalized. These patients have a high symptom burden: the main reasons for PCT referral are pain and dyspnea and the PCT on average looks at four symptoms and problems. The involvement of PCTs is associated with better quality of life after two weeks of follow-up and with better quality of dying of the patient, as perceived by the relatives. PCT consultation does not seem to have an effect on hospital treatment and related costs, although consultation within three days of hospital admission may lead to lower hospital costs. In this discussion, we will further elaborate on these findings, starting with the effects of PCT consultation and with the characteristics and determinants of PCT consultation. Furthermore, we will discuss two themes related to PCT consultation: advance care planning and end-of-life decision making. We will also discuss some relevant questions regarding the need for PCT consultation in hospitals, the extent to which PCTs in Dutch hospitals meet (inter)national standards and ways of providing palliative care in hospitals. The chapter continues with some methodological considerations. The chapter ends with recommendations for clinical practice, policy, and research.

The effects of PCT consultation on quality of life, quality of dying, satisfaction and on (costs of) hospital care of hospitalized patients with advanced cancer

Main findings:

- PCT consultation has a positive impact on pain, appetite loss and emotional functioning and seems to improve quality of life of hospitalized patients with advanced cancer. (chapter 4)
- PCT consultation is associated with a better quality of dying for hospitalized patients with advance cancer. (chapter 6)
- On several subdomains of QOD, there is a non-significant trend towards a more favorable quality of dying for patients who received PCT consultation. (chapter 6)
- Costs of hospital care are lower for patients with than patients without PCT consultation, especially when such consultations occur early during admission, which

is probably mainly due to the relatively poor health status of patients with PCT consultation. (chapter 5)

- Earlier PCT consultation in hospitals may lead to cost savings. (chapter 5)

The main objective of the COMPASS study was to study the effect of PCTs on quality of life of hospitalized patients with cancer. Our aim was to study the effect of PCTs in daily hospital practice and not in an experimental setting, although randomized controlled trails (RCTs) are considered the gold standard in research, due to the assumption of unbiased allocation of treatment and the application of statistical theory on the basis of random sampling.(1) Instead, we corrected for baseline differences using multivariable analyses and bootstrapping.

In our study, 164 patients were able to complete quality of life questionnaires after two weeks of follow-up, of whom 32 received PCT consultation. We were able to detect a significant effect of PCT consultation on pain, appetite loss and emotional functioning as measured with the EORTC QLQ C15 PAL. The symptom scores (measured as subscales of the EORTC QLQ C15 PAL) of patients with PCT consultation improved more at two weeks follow up, compared to patients without PCT consultation. Patients with PCT consultation also had better scores for physical functioning and global health status, but these differences were not statistically significant. This finding suggests that PCTs have a positive effect on symptoms and aspects of quality of life.

An observational study by Jongen et al., performed in a Dutch tertiary hospital, also reported significant improvements in pain and other symptoms after PCT consultation.(2) A recent review by Gaertner et al. on the effects of PCTs in hospitals included 10 RCTs.(3) It concluded that specialist palliative care as performed by multi-professional teams is associated with a small effect on quality of life after three months of follow up, and might have most pronounced effects for patients with cancer who receive such care early. Data on the effect of PCT consultation on pain were inconclusive.(3) A Cochrane review on the effects of early palliative care for patients with advance cancer included seven randomized trials of early palliative care. It was found that early palliative care significantly improved health-related quality of life, but the effect size was small.(4)

Recently, Vanbutsele et al. reported on the effects of early and systematic integration of palliative care in patients with advanced cancer in a university hospital in Belgium. They found a statistically significant but clinically non-significant improvement of overall quality of life in patients who received early palliative care compared with patients who received usual care, which in this study also included standard psychosocial support.(5) Gaertner et al. state that the small effects could be explained by the fact that in the included

RCTs specialist palliative care was provided to all patients, including patients who did not have high scores for pain or other symptoms, and that the potential role of general, non-specialist palliative care, that could also have been provided to patients in the control groups, was neglected.(3) In our observational study, palliative care consultation was only provided upon the request of the primary caregivers to patients with a high symptom burden. This may account for the fact that we found significant positive effects of PCT consultation in this relatively small sample of patients. A systematic review by Kavallieratos et al., that also only included RCTs, had a broader perspective and was not restricted to hospital PCTs or patients with cancer.(6) They concluded that palliative care is associated with significant improvements in quality of life and symptom burden after one to three months of follow up. In the COMPASS study, the number of patients was too small to study effects beyond two weeks.

Effect on quality of dying

Quality of dying is a multidimensional construct that has been suggested to include physical, psychological, social and spiritual aspects, and issues related to life closure, death preparation and circumstances of death, and characteristics of health care at the end of life.(7) Although the concept of quality of dying may overlap to some extent with the concept of quality of life, there are some aspects that are specific for quality of dying, such as awareness of imminent death, death preparation and life closure. There are only few studies that specifically assessed the effects of PCTs on dimensions of quality of dying, such as death preparation (8) and disease awareness.(9) Furthermore, quality of dying is an outcome that was not included in recent reviews on the effects of PCTs.(3, 6) However, we think that improving quality of dying is an important goal of PCT consultation, and an outcome that should not be overlooked when considering the effects of PCTs. Especially in hospitals, which are often not considered to be the preferred place to die, specific attention for the recognition of the dying phase is desirable.(10) As Dame Cicely Saunders already stated: “How people die remains in the memory of those who live on”.

Effect on patient satisfaction.

In the COMPASS study, we planned to study the effect of PCT consultation on patients’ satisfaction with hospital care. Two weeks after inclusion, patients were requested to fill in the INPATSAT-32, which measures satisfaction with hospital care. Hundred and five patients filled in this questionnaire, of whom 16 patients received PCT consultation. The results are reported in table 1. Satisfaction with hospital care is higher for patients for whom a PCT was consulted on almost all subscales, but in particular for satisfaction with nurses, other personnel and general satisfaction. The differences are not statistically significant, which may be due to the low number of included patients. These findings indicate that the consultation provided by the PCTs may result in higher satisfaction scores, particularly for nursing care. This is in line with results from the review by Kavalieratos et al., who found that palliative care provision was consistently associated with higher patient and caregiver satisfaction.(6) In the review by Gaertner et al., contradictory results were reported for the effect of PCT consultation on satisfaction with hospital care.(3)

Table 1: Satisfaction of patients with advanced cancer with hospital care (EORTC INPATSAT-32)

INPATSAT-32 subscales	(N=105) Mean (sd)	Patients for whom a PCT was consulted (n=16) Mean (sd)	Patients for whom no PCT was consulted (n=89) Mean (sd)
Satisfaction with physicians'†			
Technical skills	68 (22)	68 (25)	68 (22)
Interpersonal skills	67 (24)	68 (25)	66 (24)
Information	66 (24)	68 (23)	66 (25)
Availability	62 (22)	68 (22)	61 (22)
Satisfaction with nurses'			
Technical skills	72 (21)	80 (20)	71 (21)
Interpersonal skills	71 (23)	76 (25)	71 (23)
Information	67 (24)	74 (26)	66 (23)
Availability	64 (25)	70 (25)	63 (25)
Exchange of information	62 (20)	68 (19)	61 (21)
Other hospital personnel / kindness and helpfulness	60 (21)	67 (26)	58 (20)
Waiting time	61 (21)	69 (20)	60 (20)
Access (parking, means of transport, etc.)	59 (22)	64 (24)	58 (22)
Comfort /cleanness	62 (25)	61 (22)	62 (26)
General satisfaction	72 (21)	78 (22)	71 (21)

†EORTC INPATSAT-32: all items are scored from 0 to 100 where a higher score indicates a higher level of satisfaction.

Effect on hospital care and costs

We performed the first study to assess the association between PCT consultation and medical costs in hospitals in the Netherlands. The average time that was spent on a consultation, and consequently the costs of consultation, differed between hospitals. Mean costs for personnel were approximately €300 per consultation. We did not find

significant differences between patients with and without PCT consultation in volume or costs of their hospital stay, most diagnostic procedures or therapeutic interventions. We found significant differences in some diagnostic procedures (urine tests and CT's scans), which are possibly related to the fact that the hospitalizations were more often unplanned and related to symptom management in the consultation group.
The effects of PCT consultation on hospital care and costs of care have been studied in several other, predominantly observational studies. A review by May et al. in 2014 reports a clear pattern of cost savings from inpatient palliative care consultations.(11) PCT involvement may account for a better match between patients' needs and the medical treatment provided, and involve a shift in the course of treatment, resulting in less intensive hospital treatment and reduced intensive care admissions.(12) A cost analysis in an RCT of early palliative care in patients with metastatic cancer found a non-significant cost saving of on average $117 per day per patient, and significantly lower expenses for chemotherapy in patients who received early PCT consultation.(13) More recently, a meta-analysis of six observational studies was performed to estimate the association of PCT consultation within three days of hospital admission with total direct hospital costs. It was found that PCT consultation within three days of admission was associated with significant cost savings. These savings were larger in patients with cancer (on average €4151,- per hospital admission) and in patients with more comorbidities.(14) When we restricted our analysis to patients for whom the PCT was consulted during the first three days of hospital admission, we found a non-significant trend towards lower costs of hospital stay and overall costs of hospital care. Consultations that take place earlier during admission may have a more substantial effect of hospital costs, compared to consultations that take place at a later stage.

The fact that we found less impact of PCT consultation on costs of hospital than previous studies in other countries may be explained by several factors. First, in the Netherlands, costs of hospital care in the last half year of life are much lower than e.g. in the United States, where most studies on this topic were performed. Bekelman et al. found that in the Netherlands relatively few patients are admitted to an ICU and few patients receive chemotherapy in the last phase of life.(15) In the COMPASS study, the proportion of patients who received chemotherapy was already lower for patients who would receive PCT consultation at admission, compared to patients without PCT consultation. In the Netherlands, there is an open culture towards death and end-of-life care and relatively strong and longstanding emphasis on home-based care, as compared to other countries. (16, 17) Furthermore, it has been suggested that cost analysis should incorporate the timing of the intervention. An earlier intervention may involve larger cost savings.(18) This finding seems to be confirmed by our study. Third, we included patients' prognosis as a potential confounder, because many studies have shown that PCT consultation often concerns patients with a limited life expectancy which may in itself affect the use of hospital care. This is however not commonly done in other studies.(14)

Determinants and characteristics of Palliative Care Team consultation in Dutch hospitals

Main findings:

- The number of PCTs in Dutch hospitals has increased rapidly over the past ten years. (chapter 7)
- PCTs vary in their composition, annual number of consultations, and working procedures. (chapter 7)
- In the Netherlands, PCTs are involved in less than one percent of all annual hospital admissions. (chapter 7)
- PCTs in hospitals are mainly consulted for patients with cancer who have a life expectancy of less than three months, who are hospitalized unplanned and who have a lack of options for anti-cancer treatment. (chapter 3)
- Patient characteristics such as age, sex, type of cancer have no influence on whether or not a PCT is consulted. (chapter 3)
- The main reasons for consulting a PCT are pain and other physical symptoms, together with aspects involving the organization of care. (chapter 3)
- Reasons for consultation vary according to the patient's life expectancy. (chapter 3)
- In the last month of life, PCTs or palliative care consultants are involved in 12% of all people dying in the Netherlands. (chapter 9)

What is palliative care team consultation?

PCT consultation is not a standardized intervention, as we have seen in our study. In our national survey (chapter 7) we found substantial differences in PCT professionals participating in the teams, their education, in working procedures and in annual number of consultations. PCT consultation is mainly provided for inpatients, and not for patients who are seen at the outpatient clinic. In 2015, only 22% of the hospital PCTs had an outpatient clinic for palliative care. In studies on the effects of PCT consultation, it is often not clear which components of PCT consultation are causing improved patient outcomes. However, based upon current evidence, the American Society of Clinical Oncology (ASCO) states that 'palliative care for patients with advanced cancer should be delivered through interdisciplinary palliative care teams, with consultation available in both outpatient and inpatient settings'.(19) Essential components of palliative care, according to the ASCO, are described in textbox 1.

Textbox 1: Components of palliative care according to the American Society of Clinical Oncology (ASCO)(16)

- Rapport and relationship building with patient and family caregivers
- Symptom, distress and functional status management (e.g. pain, fatigue, sleep, disturbance, mood, nausea or constipation)
- Exploration of understanding and education about illness and prognosis
- Clarification of treatment goals
- Assessment and support of coping needs (e.g. provision of dignity therapy)
- Assistance with medical decision making
- Coordination with other care provider
- Provision of referrals to other care providers as indicated

Which patients receive palliative care team consultation?

Patient characteristics

Our study shows that patients for whom a PCT is consulted are mainly patients with high symptom burden who have a life expectancy of less than last three months, for whom options for anti-tumor therapy have been exhausted and who have an unplanned hospital admission. Patients with advanced cancer often suffer from multiple and severe symptoms and problems, physical, psychological, social and spiritual, which have a great impact on their quality of life and which tend to increase over time.(20-22) In cancer care, patients with 9 or 10 symptoms are common.(23, 24) In our study, PCTs reported on average 4.4 symptoms and/or problems per patient related to the consultation, which is comparable to the number found in a study in Japanese hospitals.(25) The difference between the total number of symptoms found in patients with cancer in other studies and the number of symptoms as reported by the PCTs in our study can be explained by the fact that some symptoms were already taken care of by primary caregivers.

Symptoms and problems

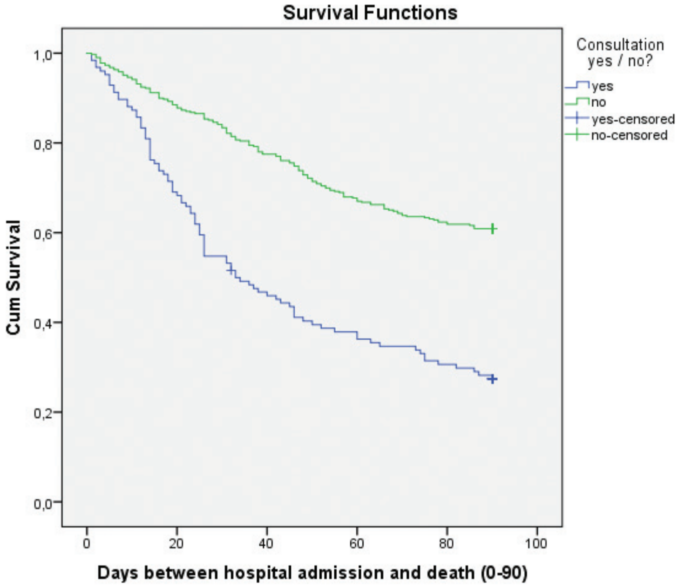
The reasons for which PCTs were most often consulted were physical symptoms and aspects regarding the organization of care, which include support with transfers to home or other settings and advance care planning. The high prevalence of physical symptoms was also found in other studies.(26-29) Existential or spiritual problems are less common: in our study 11% of all consultations involved patients who had problems with 'giving meaning' to their situation. It is known that psychological and spiritual problems less often trigger physicians to refer patients to specialist palliative care.(26) Spirituality is not a topic that is often discussed by physicians, although the frequency increases when patients have a terminal illness.(30) Discussing spirituality and religion is especially important at times of personal crisis.(31) Referral for psychological support is often initiated by nursing staff.(32) Furthermore, it is known that in hospitalized patients, symptoms are sometimes overlooked.(33)

Therefore, a structured multidimensional assessment of symptoms and problems for patients with advanced cancer may be an important tool to assure no symptoms or problems are overlooked. As our study showed that both the participating professionals in PCTs and the instruments for assessment of symptoms vary, it can be questioned whether all domains of palliative care are always assessed in all consultations.

Late referral

In the COMPASS study, only patients with an estimated life expectancy of one year or less were included. The surprise question (34) asking "Would you be surprised if this patient died within 12 months" was chosen as an inclusion criterion to guarantee that as many patients as possible for whom a PCT may be consulted, were included in the study. However, we found that teams were mainly consulted for patients with a life expectancy of less than three months who had no more options for anti-cancer treatment. The survival between both groups differed significantly. (see figure 1).

Figure 1: Survival curve of patients with and without PCT consultation (N=535.)



Late referral is not typical for Dutch hospitals. In other countries, such as the United States, referral to palliative care services also typically occurs late in the course of a patient's illness, often only after anti-cancer treatments have been exhausted.(35-38)

Late referral might be due to clinician-related, patient-related, and system-related barriers.(39) There may be a lack of awareness among health care professionals of the availability and potential contribution of PCTs, or there may be a misperception that palliative care is synonymous with end-of-life care.(40, 41) Hui et al. describe that one of the most important clinician-related barriers is the stigma associated with the service name 'palliative care'. They found that 'supportive care' as a service name was associated with a significant increase in early referral and suggest to replace the term 'palliative care' by 'supportive care', which may cause an increase in PCT consultations.(39) Other clinician-related barriers to consultation of a PCT are the lack of clear referral criteria, prognostic uncertainty, or concerns that involvement of palliative care may be seen as a signal that primary health care professionals have given up all hope for a patient.(42-44) Medical specialists may further not refer patients because they lack awareness or skills to identify palliative care needs.(45)

Patients and families may also be reluctant to accept a referral for specialist palliative care because of the association of palliative care with dying.(46, 47) In a study among 170 patients with advanced cancer, it was reported that patients preferred 'supportive care' over 'palliative care'.(48) Berkowitz states that the biggest hold up of wider acceptance of palliative care has been public perception. "Most people are not knowledgeable about palliative care. In contrast, many health care providers and the public continue to believe that palliative care is what you do when there is nothing left to do".(49)

Finally, there may be system barriers, such as lack of finances and the resulting understaffing of PCTs.(50) In our study, 24% of PCTs reported that the number of consultations exceeds their capacity.

We can conclude that our findings point to a gap between the increasing evidence on the effects of early palliative care on the one hand, and daily practice of late referral on the other.

Advance care planning and end-of-life decision making

Main findings:

- Advance care planning (ACP) positively impacts the quality of end-of-life care. (chapter 11)
- Complex ACP interventions may be more effective in meeting patients' preferences than written documents alone. (chapter 11)
- In 2010, 2.8% of all deaths in the Netherlands were the result of euthanasia. Intensified alleviation of symptoms occurred in 36.4% of all deaths and forgoing of life-prolonging treatment in 18.2%. Continuous deep sedation until death occurred in 8.2% of all deaths. (chapter 8)
- Involvement of pain and palliative care specialists is associated with a higher likelihood of receiving morphine in the last 24 hours before death, receiving intensive alleviation of symptoms, receiving continuous palliative sedation and receiving euthanasia. (chapter 9)
- The judgement of SCEN physicians of euthanasia requests is dependent on characteristics of the patient, and not on characteristics of the SCEN physician. (chapter 10)
- Psychological suffering involves a greater chance that SCEN physicians judge that requirements of due care are not met compared to physical suffering. (chapter 10)

Advance care planning as an essential component of PCT consultation

Advance care planning (ACP) is a process that enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate.(51) In the Quality Framework for Palliative Care in the Netherlands. 2017. it is stated that ACP is a standard component of palliative care, that should be raised timely and in an appropriate manner.(52) Although the term 'ACP' is not explicitly mentioned as a component of palliative care in the ASCO guideline, the performance of goals-of-care discussions that involve talking about patients' knowledge of the illness, realistic options for treatment, and care planning, is mentioned as an important part of palliative care.(19) Our review shows that ACP, especially the more extensive ACP interventions, improves quality of end-of-life care and seems to increase compliance with patients' end-of-life wishes.(chapter 11)

In our study on the reasons for PCT consultation (chapter 7), ACP was not specifically included as a pre-structured answer in the questionnaire. In our study on quality of dying (chapter 6), 10% of consultations were related to ACP. A recent study by Bischoff et al.(53), among 78 palliative care teams in hospitals in the United States, found that 72% of patients referred to PCTs were in need of care planning, especially older patients. More than half of the patients who were referred to PCTs for reasons other than ACP, were also found to have a need for care planning when seen by the PCT. PCTs engaged in care planning with most of the patients they saw, frequently clarifying both who would be the surrogate decision maker and the patient's code status. In nearly one-third of patients, PCTs identified a preference to limit life-sustaining interventions (e.g. code status such as Do Not Resuscitate (DNR) or Do Not Intubate (DNI)) that had not previously been documented. In another study by Rabow et al. among patients with cancer and other life-threatening diseases who were referred to a PCT, it was found that most patients thought about ACP and wanted to talk about it. However, extra sensitivity and attention is required to actually initiate discussions about end-of-life issues. And although the majority of patients perceived discussing ACP as difficult, they desired to have these discussions, while expecting the physician to take the lead.(54) In the recommendations of the European Association for Palliative Care (EAPC) on ACP it is stressed that implementing ACP should be based on the readiness of the patient and that health care professionals should adopt a patient centered approach when engaging in ACP. We therefore suggest that ACP should be a topic of interest for each consultation, but that it should be carefully addressed, based on the needs and readiness of the individual patient.

End-of-life decision making and PCT consultation

In the Netherlands, the percentage of patients in whom an end-of-life decision was made before death, increased over the last 25 years to almost 60% in 2015.(55) End-of-life decisions involve decisions to withhold or withdraw life prolonging treatment, to intensify the alleviation of symptoms or to perform euthanasia or physician assisted suicide. PCTs are often involved in end-of-life decision-making: almost 20% of all consultations were related to decision making regarding the withholding or withdrawal of treatment and 7% were related to decision making regarding euthanasia. Another 7% of consultations were related to palliative sedation.(chapter 3) These percentages increased as the life expectancy of the patient became worse.

Consultation of a second, independent physician is obligatory when a physician considers granting a euthanasia request. Consultation of such a second, independent physician is an important safeguard. Consultation in case of euthanasia requests is often provided by trained SCEN-physicians (Support and Consultation on Euthanasia in the Netherlands). Our study shows that SCEN physicians' judgement on whether a request for euthanasia meets the requirements of due care is associated with characteristics of the patient requesting for euthanasia, such as physical suffering and patient age. Whether or not requirements for due care were considered to be met was not associated with characteristics of the SCEN physician. Patient characteristics that are associated with a lower likelihood to meet due care requirements were: being tired with life, depression and not wanting to be a burden. Physical suffering and higher patient age were related to greater chances of meeting the requirements. (chapter 10) We did not find an indication that involvement of a PCT lowers the frequency of euthanasia requests: involvement of pain or palliative care specialist was positively associated with the performance of euthanasia. (chapter 10)

More in general, it can be questioned whether consultation of a PCT should be obligatory for specific medical decisions at the end of life, such as the decision to use palliative sedation. In the Netherlands deep continuous sedation was provided in 18% of all deaths in 2015.(55) The EAPC recommends that "whenever possible, the medical rationale for sedation as well as the decision-making process should be based on input from the multi-professional palliative care team, rather than by the treating physician alone."(56) However, in the Netherlands, palliative sedation is considered as normal medical practice by the Royal Dutch Medical Association (RDMA). Therefore, we do not think it is advisable to make consultations of a PTC obligatory in case of palliative sedation. However, in complex situations or in case the attending physician lacks expertise, consultation of a PCT is recommended.

General considerations on PCT consultation in hospitals

Do PCTs fulfill the need for specialized palliative care for patients with cancer in hospitals?

Over the past decade there has been a strong increase in number of PCTs in Dutch hospitals, especially after the release of the guidelines of the Dutch Federation of Oncological Societies (SONCOS). Specialized palliative care in Dutch hospitals is mainly provided by PCTs, and to a lesser extent by outpatient clinics and palliative care units. However, despite the increasing awareness of the importance of palliative care in hospitals, PCTs are involved in only less than one percent of all hospitalized patients, which is a low percentage compared to the number of consultations in other countries, such as the United States where 4.4% of all hospitalized patients received PCT consultation.(57)

There may be several explanations for this relatively low number of PCT consultations. First, both health care professionals and patients might be reluctant to involve a PCT as described earlier. Furthermore, as our study showed, most PCTs in Dutch hospitals have been recently established and it takes time to establish a well working team. In our study, we also found that relatively 'older' PCTs, which are more embedded within the hospital organization, have more consultations. A third reason for the low number of consultations could be that the need for specialized advice as provided by PCTs depends on both the population of patients of the specific hospital and on the level of expertise in palliative care among hospital caregivers. In Belgian hospitals, it was found that 9% of all admitted patients were in the palliative phase.(58) In the United Kingdom 36% of all hospitalized adult patients had palliative care needs according to the Gold Standards Framework criteria, whereas hospital medical staff identified 16% of patients as having palliative care needs.(59) When we look at end-of-life care in Dutch hospitals, we see that hospitalized patients with cancer receive less 'aggressive' treatment in the last phase of life than patients in other countries, and the number of intensive care admissions in the last month of life is also relatively low.(15) It is not known how many hospitalized patients with cancer have unmet palliative care needs in the Netherlands. However, several studies found that a substantial number of patients with cancer experience unmet needs in several domains.(60-62) The number of unmet needs may be less than in other countries due to the generalist approach of palliative care: general care providers, such as medical oncologists, may have been educated in (aspects of) palliative care, and be able to provide palliative care themselves. However, palliative care has only recently gained attention in the hospital setting, and basic training in palliative care is not yet standard practice in the curricula of medical students and nurses, which suggests that the level of palliative care expertise in hospitals in the Netherlands may not exceed the level in other countries. This is confirmed by the report of the Economic Intelligence Unit, where the Netherlands are ranked 22nd in the human resources category.(63)

In general, we conclude that the results of our studies on the effect of PCT consultation on quality of life and quality of dying indicate that improvements in both quality of life and quality of dying are possible, even when PCTS are consulted late in patients' illness trajectories. However, one can question whether PCTs are consulted for all patients that could benefit from such consultation.

Do palliative care teams in Dutch hospitals meet (inter)national standards?

National standards

In the Netherlands, standards for PCTs have been set in 2014 by the Dutch Federation of Oncological Societies (SONCOS). These standards have probably contributed to the increase in number of PCTs in hospitals over the past years. In these standards it is stated that all Dutch hospitals are required to have a multidisciplinary PCT by January 2017.(64) Requirements for PCTs are listed in textbox 2.

Textbox 2: Standards for palliative care facilities and expertise in hospitals according to the Dutch Federation of Oncological Societies (SONCOS)(64)

By the first of January 2017 each hospital should have a multidisciplinary palliative care team that:

- works according to general principles of palliative care (59) and uses a tool to identify the need for palliative care;
- includes at least two medical specialists and a nurse with specific expertise in palliative care. The nurse is preferably an oncology nurse or a nurse practitioner in oncology or anesthesiology. At least one of the medical specialists in the multidisciplinary team should have had specific training in palliative care, for the other team members this is strongly recommended;
- has a possibility of consultation of a medical oncologist, anesthesiologist, neurologist, pulmonologist, gastro-enterologist, radiotherapist, pharmacist, psychologist, psychiatrist, spiritual caregiver and social worker, all with expertise in palliative care, in so far as they are not already part of the multidisciplinary team;
- meets weekly;
- has a timely and structured assessment and transfer for patients who are discharged to home;
- is available for deliberation with the general practitioner for patients who are residing at home.

We found that some of the criteria as formulated by SONCOS were met by the PCTs: the large majority of PCTs uses palliative care guidelines and almost all PCTs have a weekly team meeting. Almost all teams include at least two medical specialists (most often a medical oncologist, an anesthesiologist or a pulmonologist) and have at least one nurse or nurse practitioner. Spiritual caregivers are represented in about two third of all teams, whereas both psychologists and social workers are only represented in a quarter of all teams each. The instrument most often used by the teams to identify the need for palliative care is the Distress Thermometer (65) which was used in about half of all teams. However, not all teams use a tool to identify the need for palliative care, and only half of the teams were available for telephone consultation about patients who are known to the team and who reside at home.(66) We can therefore conclude that in 2015 not all hospitals and PCTs met the professional standards set by the Dutch Federation of Oncological Societies. This could be explained by the fact that some teams had only been established recently. Furthermore, the lack of sufficient funding is a major limiting factor for the development of the teams, in the Netherlands (chapter 7) but also in other countries.(50) In the majority of PCTs, only nurses and nurse practitioners have labeled hours for their work as a palliative care consultant. Medical specialists, social workers and spiritual caregivers most often do not have no labeled hours for their activities for the PCT and have to perform their activities during their regular work. The staffing of PCTs was found to be associated with the number of consultations: in an American study, PCTs with the highest staffing levels reached 6.5% of all hospital admissions, while programs in the lowest staffing quartile only reached 2.9% of hospitalized patients.(57) In this context, it is interesting to follow up the development of the PCTs in Dutch hospitals. In 2018, the survey among Dutch hospitals is repeated by the Netherlands Comprehensive Cancer Organization, which will provide new information on the development of the PCTs in Dutch hospitals.

The Quality Framework for Palliative Care in the Netherlands

In October 2017 the Netherlands Comprehensive Cancer Organisation (IKNL) and Palliactief, the Dutch Society of Multidisciplinary Palliative Care, launched the Quality Framework for Palliative Care in the Netherlands. The framework provides standards for palliative care, with a central position for the values, wishes and needs of the patient and their families, and is endorsed by a large number of professional organizations.(52) The framework includes ten domains. Each domain is made up of an introduction, one or more standards and multiple criteria. Standards and criteria applicable for PCTs are displayed in textbox 3.

Textbox 3: Standards for interdisciplinary palliative care teams as described in the Quality Framework for Palliative Care in the Netherlands. 2017.(52)

Standard: The multidimensional approach of the patient and his healthcare requirements in the palliative care phase calls for knowledge and involvement of several disciplines working together in an interdisciplinary team. This team is formed by healthcare professionals and volunteers in close collaboration with the patient and his family.

3. In mutual agreement with the physician in charge, healthcare professionals specialized in palliative care will be involved when generalist palliative care professionals cannot meet the values, wishes and needs of the patient and his family.
4. A specialist palliative care team always consists of physicians and nurses specialized in palliative care and spiritual care givers and/or BIG*-registered psychologists and/or social workers.
5. In case of a specialist evaluation of the patient, the advice is accompanied by a step-by-step plan for continuing treatment when complaints or symptoms increase.

Standard: Both healthcare professionals and volunteers are qualified for the care they provide, and they can prove that they are keeping their knowledge up-to-date with relevant continuing education. Additional criteria for healthcare professionals with specific palliative expertise:

1. Healthcare professionals specialized in palliative care have had a certified training in palliative care and have relevant experience and skills. This allows them to fulfil the multidimensional needs of the patient and his family. They are also willing and able to collaborate as an interdisciplinary team (primary, secondary or transmural).
2. The specialized palliative-care team has the expertise required to be able to provide advice and support in specific situations with reference to e.g. children, vulnerable older people or disabled people who are involved with patients in the palliative care phase.
3. Healthcare professionals specialized in palliative care are educated and trained in self-reflection and in developing effective coping skills.
4. Expertise and skills of individual healthcare professionals and of specialized palliative-care teams should not only be acquired but also kept up-to-date and recorded, for example in a discipline-specific register.
5. Healthcare professionals specialized in palliative care provide training (such as bedside training and discipline-transcending training) to other healthcare professionals to enhance the development of generalist palliative care.
6. Healthcare professionals specialized in palliative care are used for palliative-care training in initial education and further education.
7. Healthcare professionals specialized in palliative care participate in initiatives to increase public awareness with respect to palliative care, to provide information or to increase the number of volunteers.

Standard: Providers of palliative care strive for the best quality palliative care, both in experienced quality of care and offered support for all patients and their families, healthcare professionals and volunteers, as in organization of care.

9. A specialist palliative care team organizes supervision and intervision for the team members involved and, at least once a year, has a joint evaluation of the quality of care provided, including quality measurement and quality improvement, policy and staffing.

In our survey, not all of the criteria as formulated in the quality framework were assessed. We found that over 90% of PCTs has specified requirements regarding the PCT members' education, although national consensus regarding the required education for each participating discipline is lacking. Furthermore, the vast majority of teams is involved in training of general hospital staff in palliative care. As far as we know, volunteers are not part of hospital PCTs.

International standards for PCTs

It is now widely acknowledged by the WHO and professional organizations such as the European Association for Medical Oncology (ESMO) and the American Society of Clinical Oncology (ASCO) that palliative care should be provided whenever needs are identified, irrespective of the stage of the disease, and not only at the end of life.(67) The ASCO specifically mentions the role of interdisciplinary palliative care teams and states: *"Inpatients and outpatients with advanced cancer should receive dedicated palliative care services, early in the disease course, concurrent with active treatment. Referral of patients to interdisciplinary palliative care teams is optimal, and services may complement existing programs. Providers may refer family and friend caregivers of patients with early or advanced cancer to palliative care services*".(19) The ASCO has also described the specific components of PCT consultation.(19, 68)

In the United States, leading hospice and palliative care organizations represented in the National Consensus Project for Quality Palliative Care, have issued guidelines for palliative care services in the Clinical Guidelines for Quality Palliative Care.(69) The part of guideline concerning interdisciplinary teams is presented in textbox 4. Compared to the Dutch guidelines, several other criteria are mentioned, such as the availability of PCTs for patient and families 24 hours a day, seven days a week, and regular team meetings to discuss quality of care and quality improvement. Dutch PCTs do not meet all criteria as mentioned in the guideline: most Dutch PCTs are only available during office hours, and the majority of teams can not directly be consulted by patients and relatives. Furthermore, Dutch PCTs mostly do not include specialist involved in the care of children. However, one can question whether guidelines from e.g. the United States are relevant for the Netherlands, considering differences in the health care systems and in the role of generalist versus specialist care.

Textbox 4: Guideline concerning Interdisciplinary Teamwork as stated by the National Consensus Project for Quality Palliative Care (69)

Guideline 1.3 An interdisciplinary team (IDT) provides palliative care to the patient and family consistent with the care plan. In addition to chaplains, nurses, physicians and social workers, other therapeutic disciplines who provide palliative care services to patients and families may include: child-life specialists, nursing assistants, nutritionists, occupational therapists, recreational therapists, respiratory therapists, pharmacists, physical therapists, massage, art and music therapists, psychologists and speech and language pathologists.

Criteria:

- Specialist-level palliative care is delivered through an IDT.
- The team includes palliative care professionals with the appropriate patient population specific education, credentialing, and experience, and the skills to meet the physical, psychological, social, and spiritual needs of both patient and family. Of particular importance is assembling a team which includes chaplains, nurses, pharmacists, physicians and social workers, appropriately trained and ideally, certified in hospice and palliative care, when such certification is available. The interdisciplinary palliative care team involved in the care of children, whether the child is a patient or a family member of either an adult or a pediatric patient, has expertise in the delivery of services for such children.
- The patient and family have access to palliative care expertise and staff 24 hours a day, seven days a week. Respite services are available for the family caring for neonates, children, adolescents, or adults with serious life-threatening illness.
- The IDT communicates regularly (at least weekly or more often as required by the clinical situation) to plan, review, evaluate and update the care plan, with input from both the patient and family.
- The team meets regularly to discuss provision of quality care, including staffing, policies, measurement of quality and quality improvement, and clinical practices.
- Policies are in place for prioritizing and responding to referrals and patient-family crises in a timely manner.

Methodological considerations

The COMPASS study is the first prospective, multicenter study on palliative care team consultation in the Netherlands. Contrary to several experimental studies that investigated the effects of (early) PCT consultation, we performed an observational study, that aimed to investigate the effects of PCT in daily hospital practices. Randomized controlled trials are generally considered to be the gold standard for evaluating the effectiveness of interventions. Random allocation of treatment avoids selection bias or confounding by indication.(70) Randomization, concealment of treatment allocation and the possibility of double-blind administration of the intervention are important key concepts of RCTs, which are not always adhered to in studies on the effects of PCTs. Furthermore, RCTs may have low external validity or poor generalizability due to the extensive inclusion and exclusion criteria for participants. Well-designed observational studies can be an alternative when experimentation may be unnecessary, inappropriate, impossible or inadequate.(71) In the Dutch situation where PCTs were are already implemented in the hospital setting, an observational design was considered to be appropriate. When assessing the effect of PCT consultation, confounding by indication was addressed by using multivariable regression analysis.

The COMPASS study consisted of 3 substudies:
Substudy 1: a questionnaire study in which PCTs registered their activities to calculate the costs of PCT consultation;
Substudy 2: a medical file search in three hospitals to compare care, treatment and hospital costs between patients with and patients without PCT consultation;
Substudy 3: a longitudinal study in nine hospitals to compare quality of life between patients for whom a PCT was consulted with patients without PCT consultation during a period of 3 months after hospitalization.
Originally, based on data on the annual number of consultations from six participating hospitals, we aimed to include 100 patients with PCT consultation and 300 patients without PCT consultation, to calculate costs of consultation (sub study 1), to compare medical treatment and costs of hospital care (sub study 2) and to compare quality of life (sub study 3). However, it soon became apparent that the inclusion of patients was difficult. Palliative care teams were often consulted late in the patient's disease trajectory, and patients were often considered too ill or fragile to participate in the study, especially patients for whom a PCT was consulted. Probably gatekeeping, the prevention of eligible patients from entering a study as a research subject, by nurses and physicians also played a role.(72) In order to increase the number of patients, we decided to invite six additional hospitals to participate in the study. Ultimately, the study was performed on 20 wards in 12 hospitals.

For substudy 1, we were able to collect information on 550 consultations performed by 10 PCTs. We collected data on the reasons for consultation, on the disciplines involved and the time spent on these consultations. In hindsight, it would have been interesting to collect data on the time that PCTs spend on specific components of palliative care consultation as described by Ferrell et al.(19), and Smith et al.(68), such as rapport and relationship building with the patient, establishing goals of care, symptom management and decision making. This would have given more insight in the activities of the PCTs.

Substudy 2 comprised a medical file search in three hospitals complemented with the data from substudy 3. Data were collected on 126 patients with and 409 patients without PCT consultation. In this substudy only in-hospital medical treatment and costs of care were taken into account. A methodological consideration is that in our multivariable analysis, we considered patients' life expectancy as a potential confounder, as it was both related to the intervention (PCT consultation) and to the outcome (costs of hospital care). In other studies, life expectancy is often not taken into account as a potential confounder. In the review by May et al., the authors state that "controlling explicitly for mortality raises endogeneity concerns because this is associated with our exposure variable (individuals with higher proximity to death are more likely to receive palliative care) and our outcome of interest (proximity to death is associated with increasing costs)."(14)

Another important consideration is that our study was performed from the hospital perspective as we only took in-hospital medical treatment into account. Chemotherapy that was provided in the outpatient clinic was not included in our study. Overall extramural health care costs for patients and caregivers were also not included in our study. These costs may be substantial as most people prefer to die at home, and people are in principle transferred to the home setting when possible. PCT consultation may thus increase extramural health care costs, if they facilitate earlier transfer from hospital to home. In the Netherlands, spending on medical treatment (including hospital costs) in the last 12 months of life is substantially less than in the United States, and spending on long-term care in their last year of life is substantial higher.(73) Therefore, it would be advisable to perform an economic evaluation from a healthcare, or even better, from a societal perspective. Furthermore, it would be interesting to look into more detail in medication provided to e.g. detect differences in the treatment of symptoms such as pain, which was the most common reason for referring to a PCT.

Due to the low number of patients included in the quality of life study, we were not able to perform a full cost effectiveness analysis. However, the combination of the relatively low costs of consultation, the (trend towards) positive effects on quality of life, quality of dying and satisfaction, and the equal costs for medical treatment suggest that PCT consultation may be a cost-effective intervention, especially when the PCT would be involved earlier in patients' disease course or earlier during hospitalization.

In substudy 3, patients who were hospitalized were asked to complete a questionnaire at six moments during a three month period. We were able to include 32 patients who received PCT consultation, and 132 patients who did not receive PCT consultation in this substudy. Especially patients who received PCT consultation may have been too ill to participate in this study, since filling out the questionnaires poses a substantial burden on the participants. Furthermore, the workload on the participating wards was often such that professionals had little time to include patients in the study. A study by Higginson et al. showed that recruitment rates for studies may vary based on the research burden.

According to the classification of Higginson, our study had a high research burden which may have contributed to the low number of patients participating in our study.(74) A shortcoming in this substudy is that we were not able to collect reliable data on how many patients were eligible and how many were invited to participate in the study. Although a system for reporting eligible patients and whether they were invited was set up, this was not kept up to date on all wards.

Recommendations for practice, policy and research

Our study contributes to the growing body of evidence regarding the positive effects of PCT consultation on quality of life of patients with advanced cancer. Based on our findings we conclude that in-hospital PCT consultation has a positive effect on quality of life and quality of dying in patients with cancer. Costs of PCT consultation are relatively small, and PCT consultation in the first days of hospitalization might lead to lower costs of hospital care, although we cannot draw robust conclusions on this issue based on our study. More patients could benefit from the support of a PCT when they are involved more often and in an earlier stage. In the Netherlands, about 47.000 people die of cancer each year, a number that is expected to rise to 50.000 in 2020.(75) Of patients with cancer of 65 years and older, three out of four are hospitalized in the last 180 days of life.(15) Conform the Quality Framework for Palliative Care in the Netherlands, *all* patients with an incurable and lethal illness should be identified early and receive appropriate palliative care. In the Netherlands, palliative care is considered primarily as care that should be delivered by general caregivers. Plans have been made to more extensively implement palliative care education in the curricula of nurses and physicians. At this moment however, patients do not all receive the same standard of palliative care (76) and quality of palliative care is not yet optimal.

To guarantee appropriate care for all cancer patients we recommend the following:

Recommendations for clinical practice:

- *Hospital caregivers should explicitly and timely identify patients with palliative care needs*

In the Netherlands, hospital PCTs are often involved late in the patient's disease trajectory. We recommend to involve PCTs in an earlier stage, based upon the needs of the individual patient. Involvement of a PCT should be considered when the patient enters the stage of more symptom-oriented palliation. We recommend the standard use of a screening tool to identify patients in need of palliative care such as the Supportive and Palliative Care Identification Tool (SPICT)(77), by all physicians treating cancer patients in the hospital, both in the in- and outpatient clinic, to make sure all patients who are in need of palliative care are identified. When a patient in need of palliative care is identified, palliative care should be initiated in accordance with the Quality Framework for Palliative Care. This includes a multidimensional assessment of symptoms, problems and needs, advance care planning, the drawing up of an individual care plan and coordination of care. For each patient in need of palliative care, involvement of the PCT should be explicitly considered. We recommend that all identified patients in need of palliative care are discussed with a PCT at least once, e.g. in the weekly oncology meetings / grand rounds, in order to make sure symptoms and problems on all domains are addressed, and attention is paid to issues related to coping and the individual experiences of the patient and relatives.

- *Each hospital should have special attention for patients who are dying in the hospital.*

Despite the fact that most people prefer to die at home, about a quarter of all patients with cancer die in the hospital.(78) According to relatives, the quality of dying is significantly better in case a PCT is involved. We therefore recommend involvement of a PCT in all patients who are dying in the hospital, to ensure that adequate care is provided in the physical, psychological, social and spiritual domain. Specific attention should be paid to issues related to life closure, death preparation and circumstances of death.

- *Members of the PCT should attend weekly oncology meetings / grand rounds.*

According to the SONCOS standards, PCTs should have a weekly multidisciplinary team meeting. We recommend the integration of PCTs within weekly oncological team meetings and /or grand rounds in the hospital. This way, PCTs can be involved in identifying patients with unmet needs for palliative care and can provide support and advice to the primary caregivers.

- *Efforts of general caregivers in improving palliative care should be stimulated and other models of providing specialist palliative care in the hospital should be supported.*

A large part of palliative care in hospital is provided by patients' primary health care professionals. There are many initiatives to improve palliative care, e.g. appointment of nurse champions for palliative care on hospital wards, or innovative ways for symptom management such as web applications for the monitoring of symptoms.(79) Furthermore, in some hospitals, palliative care is not only provided by palliative care teams who can provide advice for inpatients, but also in outpatient clinics for palliative care and in palliative care units. However, in the Netherlands, these facilities are relatively rare. It can be questioned whether providing (specialist) palliative care by PCTs is sufficient in delivering palliative care in the hospital setting. In a study by Casarett et al. outcomes of consultation teams were compared with inpatient units. Families of patients who received PCT consultation were more likely to report that care in the last month of life was excellent than those who received usual care, but families of patients who received care in a palliative care unit were even more satisfied.(80) Gaertner et al. argue that the coexistence of both a PCT and a palliative care unit in a hospital can contribute to ensuring optimal high-quality palliative care for patients in complex and challenging clinical situations.(81) We therefore recommend that hospital efforts to improve specialist palliative care should not solely focus on PCTs but should also consider other ways of providing specialist palliative care, such as outpatient clinics and palliative care units.

- *Improve the expertise of primary health care professionals who are involved in care and treatment of patients who are in the palliative stage of their disease. Members of hospital PCTs should play a structural role in the education of hospital professionals.*

In the Netherlands, plans have been made to implement more comprehensive palliative care education in the standard curricula of nurses and physicians. At this moment however, most primary health care professionals are not extensively trained in providing palliative care. PCTs can have an important role in educating general caregivers in palliative care, as is already done by many PCTs. Each hospital should describe how they educate their staff to meet the standards of the Quality Framework for Palliative Care in the Netherlands.

Recommendations for policy:

- *Describe the required expertise and level of education of all members of PCTs on a national level.*

Our study not only showed a large variation in members of PCTs in hospitals, their working procedures an annual number of consultation, but also in their level of education. We recommend that national organizations describe the required expertise and level of education of all members of PCTs on a national level.

- *PCTs should be financed and staffed sufficiently to meet the need for referral and follow up.*

At this moment, a quarter of all PCTs are not staffed sufficiently to meet the need for consultation in their hospital. Furthermore, a substantial part of PCT members do not have dedicated hours for their work as a PCT consultant. When PCTs would be involved earlier and more often, this implies that more financial resources are needed. In order to adequately perform their role, PCTs should be strongly embedded within the hospital. The further development and implementation of PCTs in Dutch hospitals should be supported by organizational and financial means, using the Quality Framework for Palliative Care in the Netherlands as starting point.

- *New initiatives of providing palliative care consultation and other forms of (specialized) palliative care in hospitals should be stimulated*

Providing optimal palliative care throughout the disease trajectory implies that palliative care continues when a patient is transferred from hospital to home or to another setting. Recently, some PCTs have been transforming into transmural PCTs. These PCTs may include general practitioners, community nurses, or nursing home physicians. In some cases, such PCTs can be asked to provide advice for patients residing at home or to visit patients at home if necessary. These initiatives should be supported and financial barriers should be taken away. As described above, efforts to improve specialist palliative care should not only focus on in hospital PCTs, but also consider other ways of providing specialist palliative care, such as outpatient clinics and palliative care units.

Recommendations for further research:

- *Research on the optimal timing for referral of hospitalized patients to a PCT, including the development of criteria for early identification.*

In our study we found that specialist palliative care in hospitals is mainly provided by PCTs. Only a small percentage of hospitalized patients with cancer benefit from PCT consultation, mainly patients for whom there are no more options for anti-tumor therapy, and who are hospitalized unplanned. In the literature criteria for (early) referral can be found.(82-84) However, criteria for referral to hospital PCTs in the Dutch situation, in which palliative care is considered generalist care, are still lacking. We therefore recommend to study which patients benefit most from PCT consultation.

- *Research on effective components of palliative care and the best model of provision of specialist palliative care in the hospital.*

Our study showed that hospital PCT consultation for inpatients may be beneficial for patients with advanced cancer. Consultation is a complex intervention. Complex interventions are interventions that comprise multiple interacting components.(85) A key question in evaluating complex interventions is how the intervention works: what are the active ingredients and how are they exerting their effect?(85, 86) Palliative care is a relatively young field and more studies are needed to identify the effective components of palliative care.

- *More research on the effect of PCTs on quality of dying and on the effects of PCTs on other patient groups.*

In our study we found that relatives of patients for whom a PCT was consulted, reported a higher score for quality of dying, compared to patients without PCT consultation. And, although not significant, our results showed a trend towards better scores on several aspects of QOD for patients for whom a PCT was consulted. There are however few studies that investigated the effect of PCT consultation on specific aspects of QOD, such as awareness and life closure.

Our study was restricted to patients with cancer. In the scientific literature beneficial effects for patients with other diagnosis such as heart failure, lung disease and neurological disease are described. More research on the effect of PCTs on quality of dying and on the effects for other patient groups would be desirable.

- *Development of a national palliative care registry to provide more insight in palliative care in hospitals*

Finally, we recommend the development of a national palliative care registry as a repository for information on structure, processes and outcomes of hospital palliative care programs. Existing databases, such as the death registry of Statistics Netherlands, the Nivel registry of general practice care and the Dutch Hospital Data registry can be used to provide data for this registry. Furthermore, in such a registry data on the development of palliative care programs in hospitals can be gathered, which can promote standardization of palliative care to enhance quality.

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Summary
Samenvatting
Dankwoord
About the author
List of publications
PhD portfolio

Summary

In this thesis, two main subjects are addressed. This first part of this thesis includes a description and the results of the COMPASS study, a study on the effects and costs of palliative care team consultation in patients with advanced cancer in Dutch hospitals. In the second part, additional research on consultation in palliative and end-of-life care is described. This part also addresses some topics related to consultation, such as advance care planning and medical decision making.

Part 1: The COMPASS study

In **chapter 1**, we present an overview of the development of palliative care. Subsequently, the relation between palliative care and cancer care is described, and the specific characteristics of palliative care in the Netherlands. We focus on the development of the palliative care teams (PCTs) in Dutch hospitals. Finally, we describe a special form of consultation in end-of-life care, namely obligatory consultation in case of euthanasia or physician-assistanced suicide.

Chapter 2 describes the study protocol of the COMPASS study. The COMPASS study is the first multicenter study on PCTs in Dutch hospitals. The study aims to investigate the use, effects and costs of PCT consultation services for hospitalized patients with incurable cancer in the Netherlands and consists of three parts: 1. A questionnaire study to investigate the characteristics of PCT consultation. 2. A medical file search to compare hospital care, treatment and costs between patients with and patients without PCT consultation. 3. A longitudinal study to compare quality of life between patients for whom a PCT was consulted with patients without PCT consultation.

In **chapter 3** results of the COMPASS study with respect to the determinants and characteristics of palliative care team consultation in Dutch hospitals are described. We found that patients for whom a PCT was consulted more often had a less favorable life expectancy and less favorable WHO performance status than patients for whom the PCT was not consulted. Furthermore, for 86% of the patients for whom the PCT was consulted, the admission to the hospital had not been planned. Finally, a significantly higher proportion of patients for whom the PCT was consulted had no more options for antitumor treatment at the time of admission to the hospital than patients for whom the PCT was not consulted. Other patient characteristics were not related to PCT consultation. The main reasons for consulting a PCT were pain, issues around the organization of care, fatigue and dyspnea. Consultations for patients with a shorter life expectancy are more often related to dyspnea, activities of daily living, confusion and to decisions about withholding/ withdrawal of treatment. Consultations for patients with a longer life expectancy are more often related to coping and organization of care. The average time investment per consultation of all members of the team together was 279 minutes, of which the lion's share concerned the efforts of nurses or nurse practitioners (183 minutes) followed by doctors (78 minutes).

In **chapter 4,** the effect of PCT consultation on quality of life of patients with cancer is described. A total of 164 patients consented to participate in our study, of whom 32 received PCT consultation. Of these patients, 108 were able to complete a questionnaire at day 14, of whom 19 after receiving PCT consultation. After adjusting for baseline differences, EORTC QLQ C15 PAL scores for pain, appetite loss and emotional functioning at day 14 were significantly more favorable for patients who received PCT consultation. Patients with PCT consultation also had better scores for global health status and physical functioning although not significant.

In **chapter 5** the effect of palliative care team consultation on content and costs of hospital care in patients with advanced cancer is described. We compared hospital care during three months of follow-up for 409 patients with and 126 patients without PCT consultation while taking into account possible confounding by indication. Hospital length of stay, use of most diagnostic procedures, medication, and other therapeutic interventions were similar. The total mean hospital costs were €8393 for patients with and €8631 for patients without PCT consultation; for patients with PCT consultation within three days of admission these costs were €6543. However, when taking confounding by indication into account, we did not find a statistically significant association between hospital costs and PCT consultation.

Part 2: Consultation in palliative and end-of-life care

The association between PCT consultation and quality of dying is described in **chapter 6**. In a secondary analysis of existing data, we investigated the effect of PCT consultation on quality of dying (QOD) and quality of life in patients with cancer. Relatives scored QOD on average one point higher (on a 0-10 scale) for patients who received PCT consultation (6,7 compared to 5,8). There was no difference in quality of life in the last three days of life between both groups. Involvement of the PCT mostly occurred rather late in the disease trajectory: in about 75% of all cases, the first contact with the PCT occurred within two weeks before death. There was a non-significant trend towards a more favorable outcome for patients for whom the PCT was consulted. Patients for whom the PCT was consulted had more often discussed their preferences for medical treatment, had more often been aware of their imminent death and had more often been at peace with their imminent death. Further, patients for whom the PCT was consulted and their relatives had more often been able to say goodbye. Relatives had also more often been present at the moment of death when a PCT had been consulted. However, these differences were not significant.

Chapter 7 describes a questionnaire study to investigate the extent to which palliative care is a topic of interest in Dutch hospitals: in 2015, the majority of hospitals had an assignment from the board of directors or medical staff to develop palliative care and had a steering committee implementing palliative care. Seventy-seven percent of hospitals had a PCT, a number that has increased over the past ten years. PCTs are characterized by a large variation in annual number of consultations, disciplines represented in the teams and procedures followed by the teams. The annual number of consultations for inpatients ranged from 2 to 680, with a median number of 77 consultations per year. The mean number of disciplines that were represented in the teams was 6.5. The most common disciplines were nurses (72%) and nurse practitioners (54%), physicians specialized in internal medicine (90%) or anesthesiology (75%), and spiritual caregivers (65%). Both psychologists and social workers participated in 28% of the teams. In most cases, the physicians, social workers and spiritual caregivers did not have labeled hours for their work as palliative care consultant, whereas nurses and nurse practitioners did. Most teams (77%) were only available during office hours. Twenty-six percent of the teams could not only be consulted by healthcare professionals but also by patients or relatives. On average, teams were consulted for 0.6% of all patients admitted to the hospitals.

One of the reasons for PCT consultation is the consideration of end-of-life decisions, such as euthanasia, palliative sedation or the withdrawal of life-prolonging treatment. Trends in end-of-life practices in the Netherlands are described in **chapter 8.** We assessed the frequency and characteristics of euthanasia, physician-assisted suicide, and other end-of-life practices in 2010 in a questionnaire study in which physicians provided information about a representative sample of deaths. The results were compared with similar studies that were performed in 1990, 1995, 2001 and 2005. In 2010, 2.8% of all deaths in the Netherlands were the result of euthanasia. This rate was higher than the 1.7% that was found in 2005, but comparable with rates in 2001 and 1995. Continuous deep sedation until death occurred more frequently in 2010 (12.3%) than in 2005. Of all deaths in 2010, 0.4% were the result of the patient's decision to stop eating and drinking; in half of these cases the patient had made a euthanasia request that was not granted. In 2010, 77% of all cases of euthanasia or physician-assisted suicide were reported to a review committee.

Chapter 9 describes a study on the involvement of supportive care (palliative care consultants, pain specialists, psychologists, psychiatrists and spiritual caregivers) in caring for patients in the last month of life. For this study, we used data from the study that was introduced in chapter 8. A palliative care team or consultant had been involved in the last month of life in 12% of all patients for whom death occurred expectedly; this percentage was 3% for pain specialists, 6% for psychologists or psychiatrists and 13% for spiritual caregivers. Involvement of palliative care or pain specialists was most common in younger patients, in patients with cancer and in patients who died at home. Involvement of psychological or spiritual caregivers was most common in older patients, in females, in patients with dementia and in patients who died in a nursing home. When supportive caregivers had been involved, patients had more often used morphine and end-of-life decisions were more common.

In **chapter 10** we focus on the consultation of an independent physician in case of a euthanasia request. Such consultation is one of the requirements for due care in case of a request for euthanasia. SCEN (Support and Consultation on Euthanasia in the Netherlands) physicians have been trained to provide such consultations. Based on an analysis of SCEN reports on 1631 euthanasia requests, involving 415 SCEN physicians, we found that patient characteristics that were associated with a lower likelihood to meet due care requirements were: being tired with life, depression and not wanting to be a burden. Physical suffering and higher patient age were related to a greater chance of meeting the requirements. There was no clear association between SCEN physicians' characteristics and their judgment, suggesting uniformity in their judgment.

In addition to end-of-life decision making, advance care planning is often an important topic in palliative care consultation. The results of a systematic review on the effects of advance care planning are described in **chapter 11.** Advance care planning (ACP) enables individuals to define goals and preferences for future medical treatment and care, to discuss these with family and healthcare providers, and to record and review them if appropriate. We performed a systematic review to investigate the effects of ACP. Based on our review, we conclude that there is some evidence that ACP positively impacts the quality of end-of-life care. Do-Not-Resuscitate orders were found to reduce the use of cardiopulmonary support measures, to reduce hospitalizations and to increase the use of hospice care. Do-Not-Hospitalize orders have almost invariably been shown to be related to a reduced number of hospitalizations and an increased use of hospice care. The effects of advance directives seem more diverse but they tend to be related to an increased frequency of out-of-hospital care aimed at increasing the patient's comfort instead of prolongation of life. Extensive ACP interventions may be more effective than written documents alone. They were found to result in an increased frequency of out-of-hospital care, and in increased compliance with patient wishes and satisfaction with care.

In the final chapter, **chapter 12**, the main findings of this thesis are summarized and discussed. We conclude that the number of PCTs in the Netherlands has increased rapidly over the past ten years. PCTs vary in their composition, annual number of consultations, and working procedures. PCTs are involved in less than one percent of all annual hospital admissions and are mainly consulted for patients who have a life expectancy of less than three months, who are hospitalized unplanned and who have a lack of options for anti-cancer treatment. The main reasons for consulting a PCT are pain and other physical symptoms, together with aspects involving the organization of care. PCTs seem to have positive effects on symptoms, quality of life and quality of dying. Costs of hospital care are lower for patients with than patients without PCT consultation, especially when such consultations occur early during admission. However, when taking confounding by indication into account, involvement of a PCT was not significantly associated with a reduction in costs of hospital care.

The chapter concludes with recommendations for clinical practice, policy and future research.

Samenvatting

In dit proefschrift worden twee onderwerpen behandeld. Het eerste deel betreft een beschrijving en de resultaten van de COMPASS-studie, een onderzoek naar de effecten en kosten van palliatieve teams voor patiënten met gevorderde kanker in Nederlandse ziekenhuizen. In het tweede deel wordt aanvullend onderzoek gepresenteerd naar consultatie in de zorg rond het levenseinde. In dit deel wordt ook ingegaan op enkele onderwerpen die vaak aan de orde komen bij consultatie, zoals advance care planning en medische besluitvorming.

Deel 1: De COMPASS studie

In **hoofdstuk 1** wordt de ontwikkeling van palliatieve zorg beschreven. Vervolgens wordt de relatie tussen palliatieve zorg en oncologische zorg beschreven en de specifieke kenmerken van palliatieve zorg in Nederland. Hierna wordt ingegaan op de ontwikkeling van palliatieve teams in de Nederlandse ziekenhuizen. Daarnaast wordt ingegaan op een andere vorm van consultatie bij zorg rond het levenseinde, namelijk verplichte consultatie in geval van euthanasie of hulp bij zelfdoding.

In **hoofdstuk 2** wordt het studieprotocol van de COMPASS-studie beschreven. De COMPASS-studie is de eerste multicenter studie over palliatieve teams in Nederlandse ziekenhuizen. Het onderzoek heeft tot doel om na te gaan wat de kenmerken, de effecten en de kosten zijn van palliatieve teams voor patiënten met een ongeneeslijke vorm van kanker die zijn opgenomen in het ziekenhuis. Het onderzoek bestaat uit drie delen: 1. Een vragenlijststudie om de karakteristieken van consultatie van palliatieve teams in ziekenhuizen te onderzoeken. 2. Een dossieronderzoek waarin zorg, behandeling en kosten van zorg vergeleken worden tussen patiënten waarbij wel en patiënten waarbij geen consultatie van een palliatief team plaatsvond. 3. Een longitudinale studie waarbij de kwaliteit van leven vergeleken wordt tussen patiënten voor wie wel en voor wie geen palliatief team werd geconsulteerd.

In **hoofdstuk 3** worden de determinanten en kenmerken van consultatie van palliatieve teams in Nederlandse ziekenhuizen beschreven. We vonden dat patiënten voor wie een palliatief team werd geraadpleegd vaker een minder gunstige levensverwachting en een minder gunstige WHO-performance status hadden dan patiënten voor wie geen team was geconsulteerd. Bovendien was er in 86% van de patiënten voor wie een team werd geconsulteerd sprake van een ongeplande ziekenhuisopname. Ten slotte hadden deze patiënten vaker geen opties meer voor antitumor therapie. Andere patiënt-kenmerken waren niet gerelateerd aan consultatie van een palliatief team. De belangrijkste redenen voor het consulteren van een palliatief team waren pijn, problemen rond de organisatie van zorg, vermoeidheid en kortademigheid. Consulten voor patiënten met een kortere levensverwachting hadden vaker betrekking op kortademigheid, dagelijkse activiteiten, verwardheid en beslissingen over het al dan niet inzetten of staken van een medische behandeling. Consulten voor patiënten met een langere levensverwachting hadden vaker betrekking op coping en op aspecten rond de organisatie van zorg. De gemiddelde tijdsinvestering per consult van alle leden van het palliatief team gezamenlijk bedroeg 279 minuten, waarvan het leeuwendeel ten laste kwam van verpleegkundigen of verpleegkundig specialisten (183 minuten) en artsen (78 minuten).

In **hoofdstuk 4** wordt het effect van palliatieve teams op de kwaliteit van leven van patiënten met kanker beschreven. In totaal namen 164 patiënten deel aan de studie, waarvan voor 32 patiënten een palliatief team werd geconsulteerd. Van deze patiënten konden 108 een vragenlijst invullen op de 14^{e} dag na inclusie, waarvan bij 19 een palliatief team werd geconsulteerd. Na correctie voor verschillen tussen beide groepen, waren de scores voor pijn, eetlust en emotioneel functioneren op dag 14 significant beter voor patiënten die een consult door het palliatief team ontvingen. Patiënten met een consult hadden ook betere scores voor globale gezondheidsstatus en fysiek functioneren, hoewel niet statistisch significant.

In **hoofdstuk 5** wordt het effect van inzet van een palliatief team op de behandeling en kosten van ziekenhuiszorg bij patiënten met gevorderde kanker beschreven. We vergeleken de behandeling in het ziekenhuis gedurende drie maanden voor 409 patiënten met en 126 patiënten zonder consult. Kosten van ziekenhuiszorg voor beide groepen werden vergeleken, rekening houdend met mogelijke confounding by indication. De duur van het ziekenhuisverblijf, gebruik van de meeste diagnostische procedures, medicatie en andere therapeutische interventies waren vergelijkbaar voor patiënten met en zonder consult. De totale gemiddelde ziekenhuiskosten waren € 8393 voor patiënten met en € 8631 voor patiënten zonder consult. Voor patiënten waarbij het consult in de eerste drie dagen van de ziekenhuisopname plaatsvond bedroegen deze kosten € 6543. Kosten van ziekenhuiszorg zijn lager voor patiënten met dan patiënten zonder consult, vooral wanneer dergelijke consulten vroeg tijdens de opname plaatsvinden. Wanneer echter rekening wordt gehouden met confounding by indication, is er geen statistisch significant verschil in kosten van ziekenhuiszorg tussen patiënten met en zonder consult.

Deel 2: Consultatie en zorg rond het levenseinde

De samenhang tussen consultatie door een palliatief team en kwaliteit van sterven wordt beschreven in **hoofdstuk 6**. In een secundaire analyse van bestaande gegevens onderzochten we het effect van consultatie op kwaliteit van sterven bij patiënten met kanker. Familieleden van patiënten waarbij het palliatief team was geconsulteerd beoordeelden de kwaliteit van sterven gemiddeld met één punt hoger (op een schaal van 0-10) dan familieleden van patiënten waarbij het palliatief team niet was geconsulteerd (gemiddeld 6,7 vergeleken met 5,8). Er was geen verschil in kwaliteit van leven gedurende de laatste drie dagen voor overlijden tussen beide groepen. Consultatie van het palliatief team vond meestal vrij laat in het ziektetraject plaats: in ongeveer 75% van alle gevallen vond het eerste contact met palliatief team plaats binnen twee weken voor het overlijden. Er was een niet significante trend richting betere uitkomsten voor patiënten waarvoor het palliatief team was geraadpleegd. Deze patiënten hadden hun voorkeuren voor medische zorg vaker besproken en hadden vaker vrede met het naderend overlijden. Bovendien waren patiënten en familieleden vaker in staat afscheid nemen van de patiënt en was familie vaker aanwezig op het moment van overlijden.

Hoofdstuk 7 laat zien dat palliatieve zorg een aandachtspunt is in Nederlandse ziekenhuizen: in 2015 hadden de meeste ziekenhuizen een opdracht van de raad van bestuur of van de medische staf om palliatieve zorg te ontwikkelen, en een stuurgroep voor implementatie van palliatieve zorg. Zevenenzeventig procent van de ziekenhuizen had een palliatief team, een percentage dat de afgelopen tien jaar is toegenomen. Op dit moment zijn alle ziekenhuizen verplicht om een palliatief team hebben volgens professionele standaarden. Palliatieve teams worden gekenmerkt door een diversiteit in aantal consulten, disciplines en werkwijzen. Het aantal consulten per jaar voor opgenomen patiënten varieerde van 2 tot 680 per team, met een mediaan van 77 consulten per jaar. Het gemiddelde aantal verschillende disciplines dat deel uitmaakt van een palliatief team was 6,5. De meest voorkomende disciplines waren verpleegkundigen (72%) en verpleegkundig specialisten (54%), internisten (90%) of anesthesiologen (75%) en geestelijk verzorgers (65%). Zowel psychologen als maatschappelijk werkers waren vertegenwoordigd in 28% van de teams. In de meeste gevallen hadden de artsen, maatschappelijk werkers en geestelijk verzorgers geen gelabelde uren beschikbaar voor hun werk als consulent, terwijl verpleegkundigen en verpleegkundig specialisten dat wel hadden. De meeste teams (77%) waren alleen tijdens kantooruren bereikbaar. Zesentwintig procent van de teams kon niet alleen worden geraadpleegd door professionals, maar ook door patiënten of familieleden. Gemiddeld werden teams geraadpleegd voor 0.6% van alle patiënten die waren opgenomen in de ziekenhuizen.

Een van de redenen voor het consulteren van een palliatief team is de overweging tot het nemen van een beslissing rond het levenseinde, zoals een beslissing tot het uitvoeren van euthanasie, palliatieve sedatie of tot het staken of niet starten van een behandeling. Trends in medische besluitvorming rond het levenseinde in Nederland worden beschreven in **hoofdstuk 8**. We evalueerden de frequentie en kenmerken van euthanasie, hulp bij zelfdoding en andere medische beslissingen rond het levenseinde in 2010 met behulp van een vragenlijststudie waarin artsen informatie gaven over een representatieve steekproef van overlijdens. De resultaten werden vergeleken met die van vergelijkbare studies uit 1990. 1995, 2001 en 2005. In 2010 was van alle sterfgevallen in Nederland 2,8% het gevolg van euthanasie. Dit cijfer was hoger dan de 1,7% in 2005, maar vergelijkbaar met cijfers uit 2001 en 1995. Continue diepe sedatie tot overlijden kwam vaker voor in 2010 (12,3%) dan in 2005. Van alle sterfgevallen in 2010 was 0,4% het resultaat van het besluit van de patiënt om te stoppen met eten en drinken; in de helft van deze gevallen had de patiënt een euthanasieverzoek gedaan dat niet was gehonoreerd. In 2010 werd 77% van alle gevallen van euthanasie gemeld bij een regionale toetsingscommissie.

Hoofdstuk 9 beschrijft een onderzoek naar de betrokkenheid van supportive care professionals (consulenten palliatieve zorg, specialisten pijnbestrijding, psychologen, psychiaters en geestelijk verzorgers) in de zorg in de laatste maand voor overlijden en naar de factoren die samenhangen met hun inzet. Een palliatief team of consulent was in de laatste maand van het leven betrokken bij 12% van alle patiënten voor wie het overlijden niet onverwacht kwam; dit percentage was 3% voor specialisten pijnbestrijding, 6% voor psychologen of psychiaters en 13% voor geestelijk verzorgers. Betrokkenheid van consulenten palliatieve zorg of pijnspecialisten kwam het meest voor bij jongere patiënten, bij patiënten met kanker en bij patiënten die thuis stierven. Betrokkenheid van een psycholoog, psychiater of geestelijk verzorger kwam het meest voor bij oudere patiënten, bij vrouwen, bij patiënten met dementie en bij patiënten die in een verpleeghuis stierven. Betrokkenheid van supportive care professionals was ook geassocieerd met beslissingen rond het levenseinde en het gebruik van morfine.

In **hoofdstuk 10** richten we ons op een ander type consultatie, namelijk consultatie van een onafhankelijke arts in het geval van een euthanasieverzoek in Nederland. Deze consultatie is een van de zorgvuldigheidseisen waaraan dient te worden voldaan in geval van een euthanasieverzoek. SCEN (Steun en Consultatie bij Euthanasie Nederland) artsen zijn getraind om dergelijke consulten te verlenen. Op basis van een analyse van 1631 euthanasie-aanvragen, waarbij 415 SCEN-artsen betrokken waren, werd geconcludeerd dat kenmerken van de patiënt die verband hielden met een lagere kans dat aan de zorgvuldigheidseisen was voldaan, waren: levensmoe zijn, depressief zijn en het niet tot last willen zijn van familie/naasten. Lichamelijk lijden en een hogere leeftijd van de patiënt waren gerelateerd aan een grotere kans dat aan de zorgvuldigheidseisen was voldaan. Er was geen duidelijk verband tussen de kenmerken van SCEN-artsen en hun oordeel.

Naast medische besluitvorming rond het levenseinde is ook advance care planning (ACP) vaak een belangrijk onderwerp bij consultatie van een palliatief team. De resultaten van een systematische review naar de effecten van ACP worden beschreven in **hoofdstuk 11.** Door ACP kunnen mensen hun doelen en voorkeuren voor toekomstige medische behandeling en zorg definiëren, deze bespreken met familie en zorgverleners en indien nodig vastleggen en bijstellen. We voerden een systematische review uit om het effect van ACP te onderzoeken. Op basis van de 113 geïncludeerde papers concluderen we dat er bewijs is dat ACP een positieve impact heeft op de kwaliteit van zorg aan het levenseinde. Niet reanimeerverklaringen bleken reanimaties en ziekenhuisopnamen te verminderen en het gebruik van hospicezorg te vergroten. Schriftelijk vastgelegde wensen om niet meer opgenomen te worden in het ziekenhuis leiden tot minder ziekenhuisopnamen en een toename van het gebruik van hospicezorg. De effecten van andere schriftelijke wilsverklaringen lijken meer divers, maar het gebruik van wilsverklaringen is meestal gerelateerd aan meer zorg buiten het ziekenhuis en zorg die gericht is op het verhogen van het comfort van de patiënt in plaats van het verlengen van het leven. Uitgebreide ACP-programma's lijken effectiever te zijn dan het gebruik van uitsluitend schriftelijke documenten. ACP-programma's bleken te resulteren in een toename van zorg buiten het ziekenhuis en in een verhoogde naleving van de wensen van de patiënt en tevredenheid met de zorg.

In het laatste hoofdstuk, **hoofdstuk 12**, worden de belangrijkste bevindingen samengevat en besproken. We concluderen dat het aantal palliatieve teams in Nederland de afgelopen tien jaar snel is toegenomen. Palliatieve teams verschillen in samenstelling, in aantal consulten en in werkprocedures. Palliatieve teams worden betrokken bij minder dan één procent van alle patiënten die jaarlijks in het ziekenhuis worden opgenomen. De teams worden voornamelijk geraadpleegd voor patiënten met een levensverwachting van minder dan drie maanden, die ongepland in het ziekenhuis zijn opgenomen en waarbij geen antitumortherapie meer mogelijk is. De belangrijkste redenen voor het consulteren van een palliatief team zijn pijn en andere lichamelijke symptomen, samen met aspecten van de organisatie van zorg. Palliatieve teams lijken een positief effect te hebben op symptomen, kwaliteit van leven en kwaliteit van sterven. De kosten van ziekenhuiszorg zijn lager voor patiënten waarbij een team wordt ingezet, dan bij patiënten zonder inzet van een team, vooral wanneer het consult vroeg tijdens de opname plaatsvinden. Wanneer echter rekening wordt gehouden met confounding by indication is de inzet van een palliatief team niet statistisch significant geassocieerd met een verlaging van de kosten van ziekenhuiszorg. Het hoofdstuk wordt afgesloten met aanbevelingen voor de klinische praktijk, beleid en toekomstig onderzoek.

Dankwoord

Met veel plezier kijk ik terug op de afgelopen jaren waarin ik dit proefschrift heb geschreven en waarin ik gewerkt heb op de afdeling Maatschappelijke Gezondheidszorg. Terugblikkend was het een fijne en leerzame periode. Graag wil ik alle mensen die op enigerlei wijze betrokken waren bij de totstandkoming van dit proefschrift hartelijk bedanken. Een aantal personen wil ik hieronder graag in het bijzonder noemen.

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About the author

Arianne Stoppelenburg was born om November 22, 1974 in Alblasserdam, the Netherlands. In 1993 she completed her secondary education at ‘De Lage Waard’ in Papendrecht. Afterwards, she started the study Physical Geography at Utrecht University where she obtained a propaedeutic diploma in 1994. In 1995, she attended nursing school in Rotterdam, where she graduated in 1999. She worked as a community nurse in Rotterdam and as coordinator for the Rotterdam Palliative Care Network (NPZR). In 2001, she obtained her master’s degree in Health Policy and Management at the Erasmus University Rotterdam with a master thesis on the quality of palliative care networks. Between 2001 and 2012 she worked as a policy officer at several organizations: the Netherlands Palliative Care Network for Terminally ill Patients (NPTN) / Palliactief, at Agora, the Dutch national organization for palliative care and at the Rotterdam Stroke Service. In October 2010 she started working as a junior researcher at the department of Public Health of the Erasmus MC. In 2012 she started her PhD project on the effects of palliative care teams in hospitals. In 2015 and 2016 she worked as a policy officer for the ‘Consortium Palliatieve Zorg Zuidwest Nederland’. At the moment, Arianne works as a researcher at the department of Public Health of the Erasmus Medical Center. She is also coordinator of Cascade, the academic partnership of palliative care facilities in the southwest of the Netherlands. Arianne is married to Alexander Brinkman. Together they have two daughters: Sofie (2005) and Noor (2007).

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PhD portfolio

Name:	Arianne Brinkman-Stoppelenburg
PhD period:	2012 – 2018
Erasmus MC Department:	Public Health
Promotor:	Prof. dr. A. van der Heide
Supervisor:	Dr. S. Polinder

1. PHD TRAINING

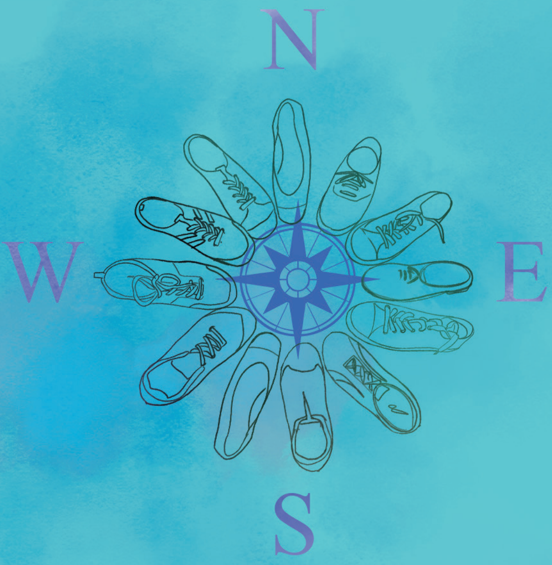
	Year	Workload
General Academic Skills		
Biomedical English Writing and Communication	2017	3 ECTS
Scientific Integrity	2017	1 ECTS
Research skills		
Master Epidemiology, NIHES	2012-2016	70 ECTS
Presentations - International		
Poster presentation: 10th World Research Congress of the European Association for Palliative Care (EAPC) Bern, Switzerland: "*The impact of palliative care consultation on quality of life of patients with advanced cancer in Dutch hospitals*"	2018	1 ECTS
Oral presentation: 15th World Congress of the European Association for Palliative Care (EAPC) Madrid, Spain: *"Palliative care consultation in Dutch hospitals, reasons for referral and costs of consultation*"	2017	1 ECTS
Poster presentation: 15th World Congress of the European Association for Palliative Care (EAPC) Madrid, Spain: "*Characteristics associated with palliative care team consultation in Dutch hospitals"*	2017	1 ECTS
Poster presentation: 9th World Research Congress of the European Association for Palliative Care (EAPC) Dublin, Ireland: *"Palliative care team consultation and quality of dying in the hospital"*	2016	1 ECTS
Poster presentation: 9th World Research Congress of the European Association for Palliative Care (EAPC) Dublin, Ireland: *"Palliative care in Dutch hospitals, results of a national survey"*	2016	1 ECTS
Poster presentation: 8th World Research Congress of the European Association for Palliative Care (EAPC), Lleida Spain: "*Supportive Care in the Last Month of Life"*	2014	1 ECTS

1. PHD TRAINING

	Year	Workload
Poster presentation: 13th World Congress of the European Association for Palliative Care (EAPC) Prague, Czech Republic: *"Effects of Advance Care Planning on End of Life Care: An Overview"*	2013	1 ECTs
Oral presentation: International Collaborative for End-of-life Care Research (ICER), Amsterdam, Netherlands: *"The effects of advance care planning- a systematic review"*	2013	1 ECTS
Presentations - National		
Mondeling presentatie: Seminar Department of Public Health, Erasmus MC: *"Palliative care consultation in Dutch hospitals, reasons for referral and costs of consultation"*	2017	1 ECTS
Poster presentatie: Nederlands-Vlaamse Wetenschapsdagen Palliatieve Zorg *"Het effect van consultatieteams Palliatieve Zorg op kwaliteit van leven van oncologische patiënten die zijn opgenomen in het ziekenhuis.*	2017	1 ECTS
Poster presentatie: Nationaal Congres Palliatieve Zorg, Lunteren *"Palliatieve teams in het ziekenhuis: steeds meer teams, Veel variatie in samenstelling, werkwijze en aantal consulten"*	2016	1 ECT
Mondeling presentatie: Erasmus MC Kennisdag Palliatieve Zorg 2017 *"De meerwaarde van de inzet van een consultatieteam Palliatieve Zorg"*	2017	1 ECT
Poster presentatie: Wetenschapsdag Maasstad Ziekenhuis *"Consultatieteams Palliatieve Zorg in het ziekenhuis: redenen om een team te consulteren en kosten van een consult"*	2016	1 ECT
International conferences		
Congresses of the European Association for Palliative Care	2013- 2017	6 ECTS
Nederlands-Vlaamse Wetenschapsdagen Palliatieve Zorg	2017	1 ECTS
National conferences and symposium		
Nationaal Congres Palliatieve Zorg	2010,2012,2014,2016	4 ECTS
Post-EAPC symposium	2015,2016	16 hours
PhD day Erasmus MC	2017,2018	8 hours

2. TEACHING ACTIVITIES

	Year	Workload
Supervision Medical Students theme 3.C4 (Community Project)	2013-2018	96 hours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