Quality Palliative Care For All

- Want it! -

Towards Death, While Alive

Manon Boddaert

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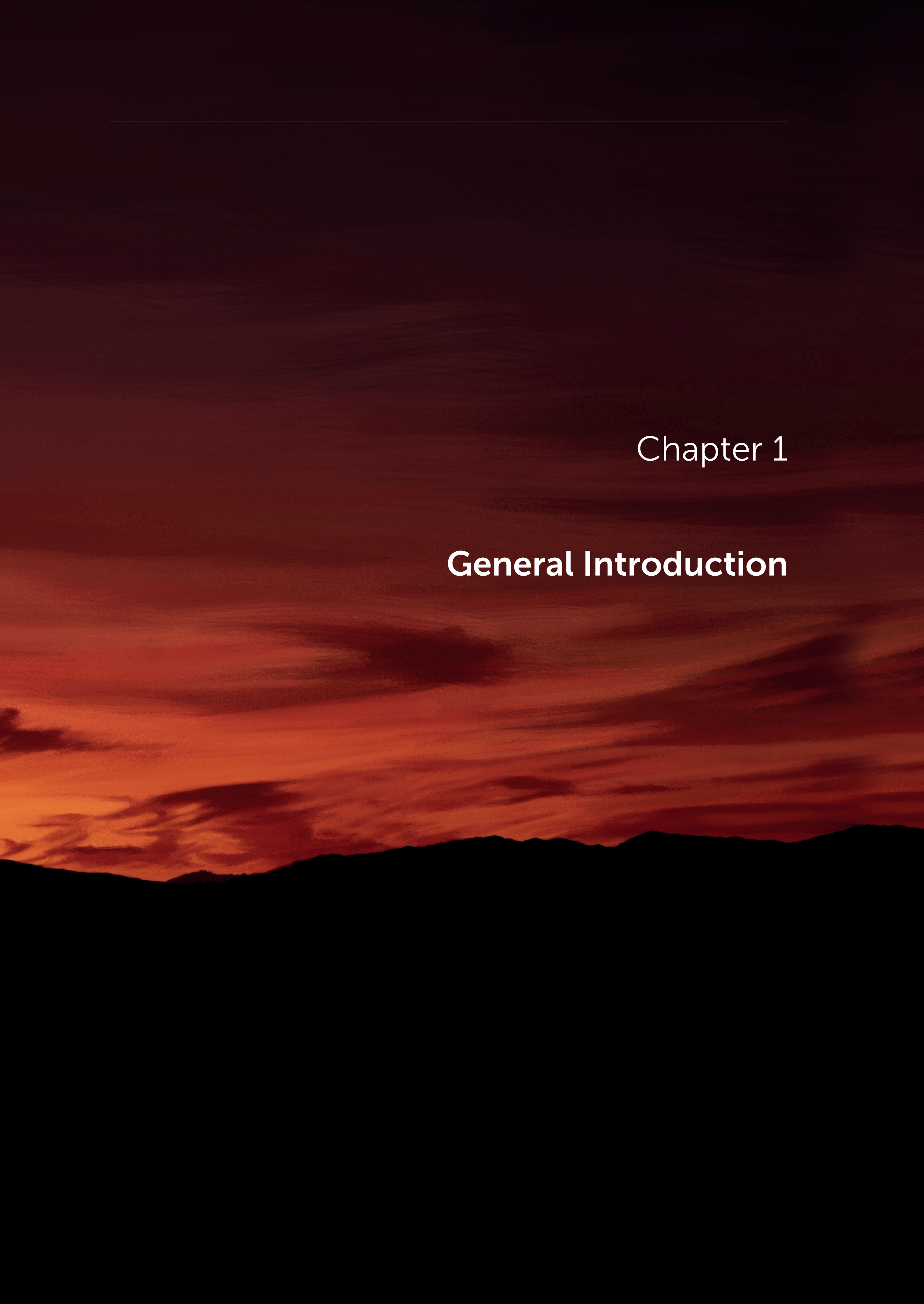


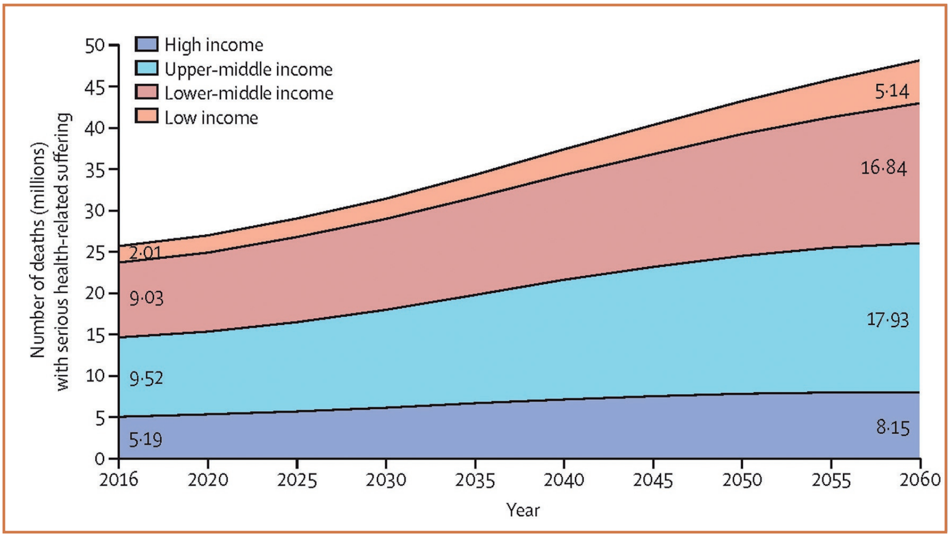
Chapter 1

General Introduction

The demography of ageing and an exponential growth of curative and rehabilitative treatments have resulted in older populations with more complex care needs.[1] Non-communicable chronic diseases are currently the leading cause of morbidity and mortality in high income countries,[2] where approximately 75% of people die from life-threatening and life-limiting illnesses, such as cancer, dementia, obstructive lung disease, heart disease and neurodegenerative diseases, with evolving and increasing health care needs.[3] Meeting these needs is putting progressive demands on society and healthcare systems.[4]

Understanding how these demands will evolve in the future is essential to develop health policies that focus on quality of life and alleviation of suffering and that prepare healthcare systems to bear the consequences of these developments . In 2019, Sleeman et al. projected the future burden of health-related suffering by combining World Health Organisation (WHO) mortality projections (2016-2060) with estimates of the prevalence of physical and psychological symptoms in 20 diseases most often requiring palliative care.[4] By 2060, an **estimated 48 million people**, i.e.,, 47% of all deaths globally, will die with serious health-related suffering. With an 87% increase from 26 million people in 2016 this indicates the burden will almost double. The fastest increases are expected to occur in low-income countries, among older people, and among people with dementia. For high income countries like the Netherlands the expected increase is around 57% (Fig 1).

Figure 1. Projected burden of serious health-related suffering in World Bank income regions until 2060.[4]



Both for this predicted increase and for an unforeseen tsunami of suffering as witnessed during the COVID-19 pandemic,[5] healthcare systems are urged to focus on the integration of palliativecare across all levels of health and social care disciplines. All healthcare professionals should be prepared and properly trained to provide generalist palliative care to their patients, and to manage patients with complex palliative care needs in close collaboration with dedicated palliative care specialists.[4 6-8]

Palliative care

In 2002 the World Health Organisation (WHO) defined palliative care as 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.[9]

Additional clarifications to the definition were that palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or 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 counselling, 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.[9]

This definition of palliative care and its additional clarifications illustrate the importance of a multidimensional whole-person approach in palliative care, that should be provided by person-centred and integrated health services paying special attention to the specific needs and preferences of each individual.[10]

Organisation of palliative care in the Netherlands

Since the late 90s, the Dutch healthcare system strives to operate an integrated generalist and specialist palliative care model similar to the model described by Quill et al. (fig. 2).[6]

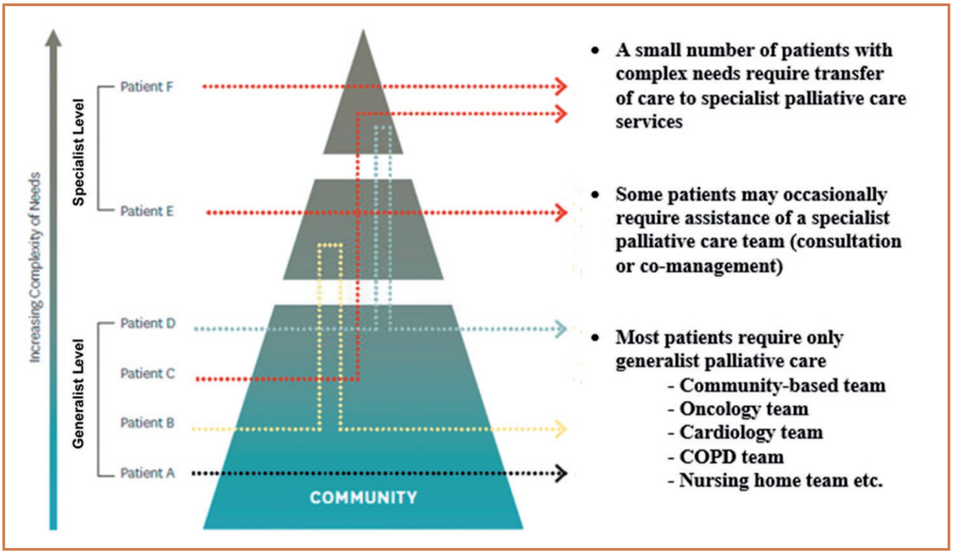
As in any medical discipline, some core elements of palliative care such as basic symptom management and tailoring treatments to a patient's goals, are considered routine aspects of care provided by any healthcare professional. Other, more complex skills require extensive training to learn and apply, such as negotiating a difficult family meeting, addressing veiled existential distress, and managing refractory symptoms. In figure 2 these skills sets for the so-called generalist and specialist in palliative care are listed.[6]

Figure 2. Skill sets for generalist and specialist palliative care provision (adapted from Quill et al.)[6]

Representative Skill Set for Generalist Palliative Care	Representative Skill Set for Specialist Palliative Care
Basic management of pain and symptoms	**Management of refractory pain or other symptoms**
Basic management of depression and anxiety	**Management of more complex depression, anxiety, grief, and existential distress**
Basic discussions about Prognosis Goals of treatment Suffering Code status	**Assistance with conflict resolution regarding goals or methods of treatment** Within families Between staff and families Among treatment teams
	Assistance in addressing cases of near futility

Integrated person-centred palliative care provision requires ongoing cooperation and coordination between generalists and specialists in palliative care, so that they can co-exist and support each other, according to the complexity of patients' palliative care needs (fig. 3).[11]

Figure 3. Proposed interaction between generalists and specialists in palliative care based on levels of complexity (adapted from LEAP Core, Pallium Canada).[11]



- **A small number of patients with complex needs require transfer of care to specialist palliative care services**
- **Some patients may occasionally require assistance of a specialist palliative care team (consultation or co-management)**
- **Most patients require only generalist palliative care**
  - **Community-based team**
  - **Oncology team**
  - **Cardiology team**
  - **COPD team**
  - **Nursing home team etc.**

Patient A – F depict patient trajectories with varying complexities of palliative care needs through time, requiring different levels of palliative care.

In the Dutch healthcare system, there is a community structure of nursing homes, family practitioners and community nurses who provide primary care and have a gatekeeping role for referral to secondary or tertiary care. Almost all medical specialties provide patient care in hospitals and outpatient clinics. Generalist palliative care should be provided by healthcare professionals in all care settings. For their support, a multitude of national palliative care guidelines is available and palliative care specialists in regional consultation teams, hospital- or community-based palliative care teams or in hospices are available for consultation or co-management, or when transfer is required in case of high complexity of needs (fig. 3).
However, since palliative care training is neither required nor fully integrated in Dutch healthcare education,[12] standards for referral or for continuity in the delivery of palliative care have not been developed,[6 11] and specialist palliative care is not recognised as a separate medical specialty or subspecialty,[13] the integration of generalist and specialist palliative care and their mutual cooperation so far has not been a naturally smooth process.

In the next paragraphs the benefits of and barriers to provision of person-centred palliative care will be addressed in relation to international and national professional and strategic efforts to support integration.

Why want it?

Envision person-centred care finding its way into everyday healthcare practice. Isn't this the type of care you would want or maybe even expect for your loved one or yourself when confronted with a serious illness? Shouldn't we all, whether general public, healthcare provider, health insurer, manager or policymaker, strive to enable healthcare systems to provide this person-centred care? Can it be that hard or complicated to realise?

John is a 38-year-old car mechanic who was sadly and completely unexpectedly diagnosed with advanced gastro-intestinal cancer. While trying to come to terms with his changed life perspective, he is being treated with chemotherapy in an attempt to control the disease as long as possible. Even though he and his wife Karin are visiting his oncologist in the outpatient clinic to discuss the results of a recent scan, John already decided before this visit to stop his treatment regardless whether the chemotherapy is effectively stabilising the disease or not. He feels that his quality of life is too low to continue, as he is bedridden for almost 2,5 weeks of the 3-week cycle of chemotherapy, due to severe nausea and vomiting. Although he takes all his anti-emetic medications as per protocol and his oncologist has tried to optimize the dosages, nothing seems to ease his constant heavy feeling of nausea. As the scan shows the tumour has decreased in size, his oncologist tries to motivate John to continue treatment. In an effort to improve his quality of life he refers the couple to the hospital's specialist palliative care team.

As palliative care entails a multidimensional approach, a detailed history reveals the full extent of a seriously reduced quality of life not only physically, but also emotionally, socially and existentially for both John and Karin. Reading a newspaper, watching TV, ordinary daylight and the smell of cooking all aggravate John's symptoms. As a result, he spends full days in bed, laying still and curtains closed, while Karin has to go to the neighbours to cook and eat her dinner. "If this is my life for the time I have left, without energy to be a husband, a son, a friend or a colleague, I no longer want to live like this", he sighs.

However, the history also reveals that John's symptoms are not only triggered by daylight and smells, but also by changes in position. This could indicate that neurotransmitter receptors in the vestibular system are involved in causing his nausea. Receptors that are not inhibited or blocked by his current medications against nausea and vomiting.

After carefully discussing and weighing pros and cons of continuing treatment or discarding it in favour of quality of life, they agree to try one last cycle of chemotherapy with a changed combination of anti-emetic medications that addresses the vestibular system as well.

Only four days after chemotherapy infusion, John calls the palliative care team to tell them that he is no longer feeling nauseous and is back in his garage tinkering with his cars. Both John and Karin maintained satisfactory quality of life while he continued with chemotherapy until finally, his disease progressed. Along the palliative care trajectory of John's disease, both his and Karins physical, emotional, social and existential needs were identified, conversations about their wishes and values in life and preferences in care were held and care was coordinated accordingly.

Benefits of person-centred palliative care

In the situation of John and his wife Karin, due to refractory symptoms palliative care specialists were integrated early in the multidisciplinary team caring for them. Subsequently, both of their needs, wishes and preferences were regularly assessed and person-centred palliative care was provided concurrently with disease-modifying treatment. This resulted in lower symptom burden and improved quality of life. This coincides with the proven benefits of palliative care provision including 1) better quality of life for patients; 2) reduced caregiver burden; 3) less potentially inappropriate end-of-life care; 4) less healthcare costs in the last months of life.

Better quality of life

Over the past decade, there is a growing body of evidence that for patients with a serious illness, integration of specialist palliative care and regular care is better than regular care alone [14-17] and early specialist palliative care is better than late,[18 19] with regard to quality of life, symptom burden, and patient and caregiver satisfaction for patients with advanced cancer.[7] In 2010, Temel et al. reported a landmark randomised controlled trial comparing patient outcomes among 151 patients with lung cancer randomly assigned to receive either early specialist palliative care integrated with standard oncology care or standard oncology care alone.[14] At 12 weeks patients provided with early palliative care showed significantly better quality of life, and less symptoms of depression and anxiety. In addition, these patients showed longer survival. A similar trial in 2018 in Belgium studied patients with cancer randomised to either receive early systematic specialist palliative care and standard oncology care, or standard oncology care alone, in a setting where all patients were already offered psychosocial care as part of standard oncology care.[16] Results showed that early systematic integration of specialist palliative care in standard oncology care increased the quality of life of patients. In addition, early systematic integration of palliative care was more beneficial for patients than palliative care consultations offered on demand, even when psychosocial support had already been offered. A systematic literature review including multiple studies of palliative care programmes in different countries and health care systems shows that integration of specialist palliative care and standard care improves symptom control and / or quality of life.[20] This is true for patients with advanced cancer[7 14-16 18] as well as patients with other life-limiting diseases,[21-24] and for patients in hospital setting as well as patients in homecare setting.[21 23 25]

Reduced caregiver burden

Among family caregivers the stress of taking care of their loved one with a serious illness is associated not only with increased prevalence of depression, anxiety, and other mental health problems but also with an increased risk of morbidity and medical illness.[26] Studies show an interdependent relation between experienced health problems in caregivers and outcomes in patients. In a meta-analysis of caregiver-wellbeing and patient outcomes in heart failure, higher caregiver strain was associated with worse patient symptoms and worse patient quality of life.[27] In addition, severe grief and depressive symptoms already existing in the caregiver before a patient's death strongly predicted complicated grief and post-loss depressive symptoms.[28]

Due to substantial heterogeneity in studies, systemic reviews and meta-analyses are as yet inconclusive about the effect of palliative care on caregiver well-being.[20 27] However, a recent study that assessed the quality of life and quality of care as experienced by patients with advanced cancer and their relatives, demonstrated the relatives' emotional functioning e.g., feeling tense, worried, irritable or down, was associated with quality of care as experienced by both patients and themselves. With regard to the family-centredness of palliative care, being more satisfied with care in general and clarity about the key health-care provider, experienced continuity of care and information for the patient were positively associated with better emotional functioning.[29] Furthermore, spouses of deceased loved ones who received hospice care may have a lower mortality rate than spouses whose loved ones did not receive it, as hospice care prepares the family for the imminent death.[30] A randomised trial in which caregivers of patients with advanced cancer received either early or delayed palliative care showed that early palliative care for caregivers led to lower depression scores and lower stress burden.[31]

Less potentially inappropriate end-of-life care

For patients with a serious illness, medical treatments which are justifiable earlier in the disease trajectory can turn into unwanted or inappropriate interventions near the end of life, where benefits of treatment no longer outweigh the possible negative effects of continuing treatment.[32] Thus, inappropriate end-of-life care has a negative impact on a patient's quality of life at the end of life. [33 34] Several studies on the integration of specialist and/or generalist palliative care with standard care show less healthcare utilisation at the end of life, i.e., less potentially inappropriate end-of-life care, for both patients with advanced cancer and patients with other life-limiting diseases.[14 21 22 35]

Less health care costs in the last months of life

In a comprehensive literature review of available international data on the costs and cost-effectiveness of palliative care interventions in any setting (e.g. hospital-based, home-based and hospice care) palliative care was most often found to be less costly than control groups receiving standard care.[36] A recent meta-analysis of the association between early specialist palliative care consultation (3 days after admission) and direct hospital costs compared to standard care showed a statistically significant reduction in costs per patient (-$3237; 95% CI, -$3581 to -$2893; P < .001).[37] The study population comprised hospitalised patients with at least one of seven serious illnesses (cancer; chronic obstructive pulmonary disease; heart, liver, or kidney failure; AIDS/HIV; or selected neurodegenerative conditions). In stratified analyses, there was a reduction in costs for both cancer (-$4251; 95% CI, -$4664 to -$3837; P < .001) and noncancer (-$2105; 95% CI, -$2698 to -$1511; P < .001) subsamples. The reduction in cost was greater in those with 4 or more comorbidities than for those with 2 or fewer.[37] A Dutch non-randomised study in 12 hospitals assessed health care costs for hospitalised patients with cancer, either with or without specialist palliative care team consultation. Eligibility for and timing of referral was determined by the oncology care team. Results showed a small non-significant difference in favour of patients with specialist palliative care, as total mean hospital costs were €8,393 for patients with and €8,631 for patients without specialist palliative care. However, patients with specialist palliative care had a significantly worse life expectancy and performance status, and more often had no more disease modifying treatment options in comparison to patients without specialist palliative care consultation. Earlier consultation may well be beneficial for both patients and reduction of costs of care.[38]

Professional efforts for integration of palliative care

In 2014, in view of the projected growth of health-related suffering worldwide, and in response to the reported benefits of palliative care, the WHO called for standardised availability, equitable access and high quality palliative care as a human right, and for the strengthening of generalist and specialist palliative care as components of integrated care throughout the patient's life.[39] To improve integration of palliative care and regular care, the American Institute of Medicine and the American and European oncology societies (ASCO and ESMO, respectively) have since recommended early and routine co-management of their patients by palliative care specialists.[40-42] Similarly, in 2014 professional oncology standards issued by the Dutch Federation of Oncology Societies (SONCOS) stated that as of January, 2017 every hospital providing cancer care should have a specialist palliative care team available.[43]

However, within a predominantly biomedical healthcare model focused on cure like most developed, high-income countries such as the Netherlands operate, it currently still appears challenging to structurally provide optimal, person-centred palliative care.[44-46]

In a recent survey, 572 executives, clinical leaders, and clinicians directly involved in health care delivery and palliative care programmes across the United States

(US) estimated that 60% of patients who could benefit from palliative care were not receiving it.[47] This implicates that palliative care services are not available to all patients with serious chronic illnesses as a matter of course. Suggestions for improvement focused mostly on staffing of palliative care specialists, additional training for palliative care generalists (both primary care physicians and medical specialists) and increasing awareness of patient populations with palliative care needs. A Dutch survey among 456 bereaved relatives compared quality of palliative care provided to patients with cancer, frailty or organ failure across various healthcare settings. Compared with the bereaved relatives of patients with cancer, bereaved relatives of patients with organ failure or frailty were more likely to negatively rate the palliative care provided to both the patient and themselves. Improving healthcare professionals' expertise in palliative care for people with non-cancer conditions was therefore recommended.[48] In a recent Dutch study exploring the needs and experiences of patients with incurable cancer with regard to the conversation in which they were told that their cancer was incurable, patients reported a strong need for emotional support during such conversations. Over one third of patients felt they did not receive any additional care after the diagnosis and the majority expressed a clear need for psychosocial care. Their experienced satisfaction with received emotional support was mediocre. Regarding conversations about the end of life, most patients expressed a need to discuss this topic, and preferred their healthcare providers to initiate such conversations.[49] Although around 70% of the annual deaths in the Netherlands concern patients who died from non-communicable chronic diseases and presumably had palliative care needs, little is known as yet about the number of patients that are actually provided with either generalist or specialist palliative care.[50]

What's the holdup?

So, why aren't all patients diagnosed with a life-threatening chronic illness requesting referral to specialist palliative care? Why aren't health care organisations developing integrated palliative care services and healthcare professionals referring patients to palliative care specialists?

Mary is an 87-year-old lady who lives on her own. She has a medical history of congestive heart failure and type II diabetes and she has recently been admitted to the hospital because of cardial decompensation. She is physically impaired due to arthritis and uses a walker. She is clear-headed, manages her medication and performs most activities of daily living independently. Community nurses come in daily to aid her with compression stockings.

Mary has never been married and has no family of her own, but she is socially active in church and plays bridge with her neighbours on a regular basis. Several good friends help her with doctors' visits and errands. She prefers to spend much of her time at home and has a strong wish, when her time comes, to die there. Mary frequently experiences pain and shortness of breath that reduce her quality of life and worry her, because her last hospital admission made her feel confused and unable to stop fearing she would die there. Should her condition deteriorate, she would rather stay home with help from her family doctor and community nurses than be admitted to the hospital again. Even if this would mean an earlier end of her life. However, the right moment to broach a difficult conversation like this with her doctor has not presented itself yet. She fears she might disappoint him and give the impression she is giving up on life.

On a Friday evening, one of Mary's friends gets a phone call for help as a result of Mary setting of her alarm device. He finds her on the floor of her apartment with severe pain in her leg after tripping and falling. Her family doctor is not available out of office hours and her friend does not know what to do other than to call an ambulance. Mary is admitted to the hospital with a broken leg. During the admission her physical and mental condition deteriorate as a result of her immobility and increased pain medication and she experiences a lot of stress and fear. With the intention to ease her anxiety and to support her in regaining mobility, she is temporarily transferred to a rehabilitation unit. Her family doctor receives a short discharge letter describing the situation and the changes in medication. When he visits Mary several days later, she is feverish, incoherent and confused and he suspects she has an infection. As he is unaware of her preferences, Mary is once again admitted to the hospital with both pneumonia and heart failure. Unfortunately, the treatment started is unsuccessful and Mary dies in the hospital after two days of terminal restlessness.

Barriers to the provision of person-centred palliative care

In Mary's case, despite her frailty due to multimorbidity and high age, none of the healthcare professionals involved initiated conversations with her about end-of-life preferences or advance directives. Thus, her care was not coordinated according to her wishes. This led to a potentially avoidable second hospital admission and high symptom burden. In the end, Mary didn`t die at her preferred place of death.

Unfortunately, this case is no exception. Identified barriers to timely palliative care provision include: 1) lack of awareness; 2) lack of education and training; 3) cultural values and beliefs; 4) fragmented healthcare systems and poor interdisciplinary teamwork.

Lack of awareness

The general public, patients, and healthcare professionals are frequently unaware of the benefits of specialist palliative care and how and when to access it.[51] In a recent scoping review of 12 studies between 2011 and 2020, 66 - 71% of the general public reported no awareness of palliative care, and those who reported awareness mostly perceived it as limited to hospice or end-of-life care.[52] Patients and their families often have misconceptions about palliative care or lack palliative care knowledge. In two recent reviews, low awareness about palliative care or about individuals or centres providing palliative care or hospice care were recurrent barriers. More than half of the patients lacked information about palliative care or hospice care.[53 54] Health professionals showed lack of knowledge of palliative care in general, e.g. how and when to initiate palliative care, and of the broad applicability of palliative care, e.g. belief that palliative care is not appropriate for those who have complex problems without physical symptoms.[53]

Lack of education and training

A systematic review of 37 studies indicated generalist palliative care in hospitals is perceived and provided as care in the last weeks and days of life. Most healthcare professionals professed a lack of sufficient training and skills in pain and symptom management, (end of life) communication, and care coordination. [55] This has similarly been reported in other systematic reviews, regardless whether they cared for patients with cancer, heart failure or chronic obstructive pulmonary disease.[55-57]

Having conversations with patients and their families around goals of care, prognosis and issues relating to mortality were described as challenging. Lack of confidence or expertise, an uncertain prognosis, a fear of abandonment or saying the wrong thing, a feeling of failure and defeat and not having built a relationship with the patient were identified as barriers.[55 58] A survey among 1589 Dutch physicians showed 64% found it difficult to talk with patients about approaching death and 67% believed physicians in general wait too long to initiate such conversations.[59] In a subsequent survey commissioned by the Steering Committee for appropriate End-of-Life care, possible reasons for these issues were addressed among 915 healthcare professionals. Nearly half indicated that such conversations are too difficult for physicians (46%), with regard to both the subject matter and communication skills. Physicians can also feel that they have got nothing to offer the patient if they are not actively treating them (13%). The latter aspect is particularly the case amongst physicians who have insufficient knowledge of palliative care, and therefore do not know what to offer the patient.[60]

Cultural values and beliefs

The challenge to providing optimal, person-centred palliative care is not solely determined by a predominantly biomedical healthcare model that is primarily focused on diagnosis and treatment.[44-46 60] The healthcare system operates within a society with culturally determined values and beliefs. The Royal Dutch Medical Association commissioned a survey study to address these contextual mechanisms and cultural aspects in healthcare.[60] Of 1648 respondents (597 general public and 915 healthcare professionals) two thirds agreed that the default attitude in Dutch society is to fight the disease and that discontinuing treatment is not an option. More than 80% agreed that end-of-life care is often too heavily focused on survival and prolonging life, and not enough on quality of life. Additionally, they indicated our society should come to terms more with the fact that life is finite. In the group of healthcare professionals, a third of respondents indicated that physicians find conversations to be too emotionally difficult with regard to delivering bad news to the patient as well as dealing with both the patient's emotions and the physician's own emotions.[60] Doctors are trained to cure people and are reluctant to raise the topic of ceasing or foregoing treatment, because they do not wish to deny their patients hope for recovery.[61-63] In turn, patients' false optimism about recovery is not only the result of physicians withholding information. On the contrary, patients seem to accept gratefully every opportunity offered by physicians to "forget" the future and to focus on the present of treatment options.[61 64] As patients associate hope with power or control and loss of hope with suffering,[65] receiving further treatment allows patients to shift attention away from the approaching last stage of life.[64] This creates what is sometimes referred to as the 'coalition of hope'.[61] Other perceived barriers identified by healthcare professionals included denial / non-acceptance by the patient and family, and reluctance on the patient or family's part to talk about a worsening prognosis. Ethnic and cultural differences influencing the patient and family's perception and practices in relation to palliative care issues and dying, such as concealing illness or prognosis from patients, were also evident.[55]

Fragmented healthcare systems and limited interdisciplinary teamwork

Patients in a palliative care trajectory face challenges brought about by the disease as well as by complicated and fragmented healthcare systems, which require coordination between healthcare professionals, various healthcare settings, and diagnostic and treatment interventions.[55 66] Inadequate handovers of care between hospital and home can lead to adverse health outcomes.[67 68] Patients at the end of life are particularly at risk, because of complex health problems that are prone to exacerbate, frequent care transitions, and involvement of many professionals.[69] A study in 2017 investigated Dutch health care providers' views and experiences with regard to the transition from hospital to primary care in palliative care. Professionals emphasised the importance of proper handovers and transitional processes in these vulnerable patients. The transition between hospital and primary care is hindered by a lack of identification of the palliative care trajectory and uncertainties about the patients' and caregivers' awareness of prognosis. Direct communication between professionals is needed but lacking. The handover itself is currently primarily focused on physical aspects where focus on psychosocial aspects was also found necessary. Furthermore, uncertainties with regard to physicians' responsibility for the patient seem to further hinder professionals in the transitional process.[70]

Most hospitals and primary care organisations in the Dutch healthcare system support initiatives to realise improvements in palliative care for patients and their families, as they can often be temporarily funded by health insurers or quality improvement programmes of national organisations such as the Netherlands Organisation for Health Research and Development (ZonMw). In general, however, over the past years they have been struggling with organisational and regulatory barriers to optimise subsequent structural provision of palliative care with regard to adequate coordination and continuity of care across hospital- and community care settings.[71 72] Separate reimbursement systems for hospital and out-of-hospital care and monodisciplinary reimbursement based on fee-for-service instead of interdisciplinary reimbursement based on value or quality made implementation across care settings complex.[60]

These barriers result in poor interdisciplinary communication and teamwork in combination with a lack of early identification of patients with palliative care needs and a mutual reluctance to communicate and create prognostic awareness and discuss preferences. This leads to sub-optimal palliative care provision.[73]

Development of palliative care in the Netherlands

Policies for members of the European Union

Since the end of the 90s the Council of Europe has focused on questions of end-of-life care and over the past decades the gradual expansion of palliative care services has been a remarkable achievement of health care development across Europe.[74 75] In 2018, in its most recent resolution "the Provision of palliative care in Europe" the Council views to ensure access to quality palliative care for everyone who needs it. Therefore, it urges member states to recognize palliative care as a human right and fully integrate it into their healthcare system. They should remove all obstacles that restrict access to pain-relieving medication in the context of palliative care, and ensure adequate training on palliative care for healthcare professionals. They should also provide comprehensive support for informal caregivers, including respite services (i.e., occasional or intermittent temporary relief from the perceived responsibilities for the care, wellbeing and safety of a person living with a life-limiting illness).[76]

National policies

Since 1998, palliative care has been a dedicated, structural part of the Dutch government's health policy improvement programme. In 1999 the Ministry of Health, Welfare and Sport commissioned and financially supported six academic centres of palliative care to establish Centres for Development of Palliative Care (COPZ) focussing on an organisational structure of palliative care provision, development of regional palliative care networks, education for all healthcare professionals and research. This was part of a wider set of reforms seeking to integrate Dutch hospice provision within the formal health care system.[74] Since then, the Netherlands Organisation for Health Research and Development (ZonMw) has offered five subsequent multiple-year incentive programmes with funding for research, development and implementation of palliative care.[77] The earlier COPZs have since transformed into seven academic centres of expertise in palliative care and together with the Ministry of Health, Welfare and Sport they initiated a National Palliative Care Programme (2014 – 2020) to work together to continually improve organisation, education and research in palliative care. Around the same time a care standard for palliative care was published as a first step to improve identification of the palliative care trajectory and to recognise and acknowledge palliative care needs in a patient. Unfortunately, broad recognition and integration of palliative care across care settings was not achieved.[78]

Balancing quality and quantity of life

In 2012, the aforementioned survey among 1589 Dutch physicians demonstrated that the majority believed patients in the last phase of life were being overtreated with inappropriate medical interventions.[59] Concurrently, in an effort to find a balance ethically, between prolonging life and quality of life, and to find a way economically to limit the rising costs of healthcare, national policymakers were questioning whether or not it was appropriate to prolong life of seriously ill patients at all cost.[77] Subsequently, the report of the Royal Dutch Medical Association Steering Committee for appropriate End-of-Life care addressed these issues.[60] Reasons for prolonging treatments and not providing person-centred PC seemed to be rooted in a culture of non-abandonment, treatment as a default mode, lack of training or emotional reluctance to talk about worsening of prognosis and death, as well as financial incentives being directed at fee for service instead of value-based healthcare.[60]

A way forward for palliative care

Recommendations of the Steering Committee for appropriate End-of-Life care aimed at integrating person-centred care and disease-modifying treatment by improving shared decision making – advance care planning; coordination of care between care transitions; communication and symptom management skills of all healthcare professionals; interdisciplinary teamwork and early referral to specialist palliative care for complex patients.[60]

This raised the opportunity for the Netherlands Comprehensive Cancer Centre (IKNL) and the Dutch Society for Professionals in Palliative Care (Palliactief) to initiate development of a national quality framework for palliative care that carried broad consensus and recognition among both palliative care generalists and specialists. In this process the previously published standard for palliative care served as a core document.[78]

Following these developments, the Netherlands Association for Palliative Care (PZNL) was founded in 2018 as a collaborative initiative of palliative care organisations supporting the structural integration of palliative care in all care settings.

Aims and outline of this thesis

The aim of this thesis is to gain a better understanding of the value, availability and accessibility of palliative care in a mixed generalist specialist palliative care model as it is operated in the Dutch health care system. In addition, it aims to provide insight into the process of developing a national quality framework for palliative care and present the key elements of quality palliative care for integration with regular care.

The following research questions will be addressed:

1. What is the current practice of specialist palliative care teams in hospitals in the Netherlands and what are their characteristics?

2. How have specialist palliative care teams developed over time and what characteristics are associated with a high referral rate?
3. What is the association between (early) palliative care and potentially inappropriate end-of-life care for patients with cancer in the Netherlands?
4. How can a national quality framework for improvement of availability and access to high-quality palliative care be developed in a mixed generalist-specialist palliative care model?

Outline

Chapter 2 and 3 describe the current practice of specialist palliative care provision in Dutch hospitals and what may be means for improvement based on two surveys among all Dutch hospitals (2015 and 2017). **Chapter 2** assesses the nationwide availability of specialist palliative care teams in hospitals and their reach of patients with palliative care needs in 2015. Subsequently, **chapter 3** describes the characteristics of specialist palliative care teams in hospitals in 2017 associated with high service penetration in order to inform further improvement of these hospital teams.

Chapter 4 and 5 address potentially inappropriate end-of-life care and the association with palliative care provision. **Chapter 4** describes a nationwide population-based observational study of administrative databases, in which healthcare utilisation in the last month of life in 2017 was compared between patients with cancer who received or did not receive timely palliative care. **Chapter 5** reports a retrospective database analysis in two acute care hospitals examining the impact of provision, timing and initial setting of specialist palliative care. **Chapter 6** describes the process of development and consensus-building of a national quality framework for the optimal organisation and delivery of patient-centred palliative care in a mixed generalist-specialist palliative care model and key elements for integration.

Chapter 7 concludes this thesis with a general discussion of the overall results and the methods that were used to obtain them, and considers implications and recommendations for clinical practice, education, policy and research.

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Chapter 2

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

Specialist palliative care teams in hospitals have positive effects on the quality of life and satisfaction with care of patients with advanced disease. 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%), medical specialists in internal medicine (90%) and anaesthesiology (75%) and spiritual caregivers (65%). In most cases, the medical specialists did not have labelled 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 healthcare 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 annual hospital admissions.

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.

Introduction

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. Specialist palliative care teams (SPCTs) 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 which distinguishes generalist 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, SPCTs are available throughout the country since the start of this century. Currently, 30 regional SPCTs are mainly consulted by general practitioners, nursing home physicians and home care nurses, but not by hospital-based healthcare professionals.[2]

In the Netherlands, two thirds of patients with advanced incurable disease are admitted to hospital sometime 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] SPCTs 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 SPCT by 2017.[12]

This development underlines the important role SPCTs are expected to play in supporting professional caregivers by providing specialist palliative care. The aim of this study is to investigate the number of hospitals that currently have a SPCT 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 2 oncology centres. The key professionals were healthcare 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%); response 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 SPCTs.

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 SPCT 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 SPCT, if applicable. Questions were asked about the disciplines that were represented in the SPCT, the procedures followed by the team, the number of consultations, team meetings and quality assurance procedures.

Statistical analysis

We analysed the data using SPSS version 20.

Results

Palliative care in hospitals

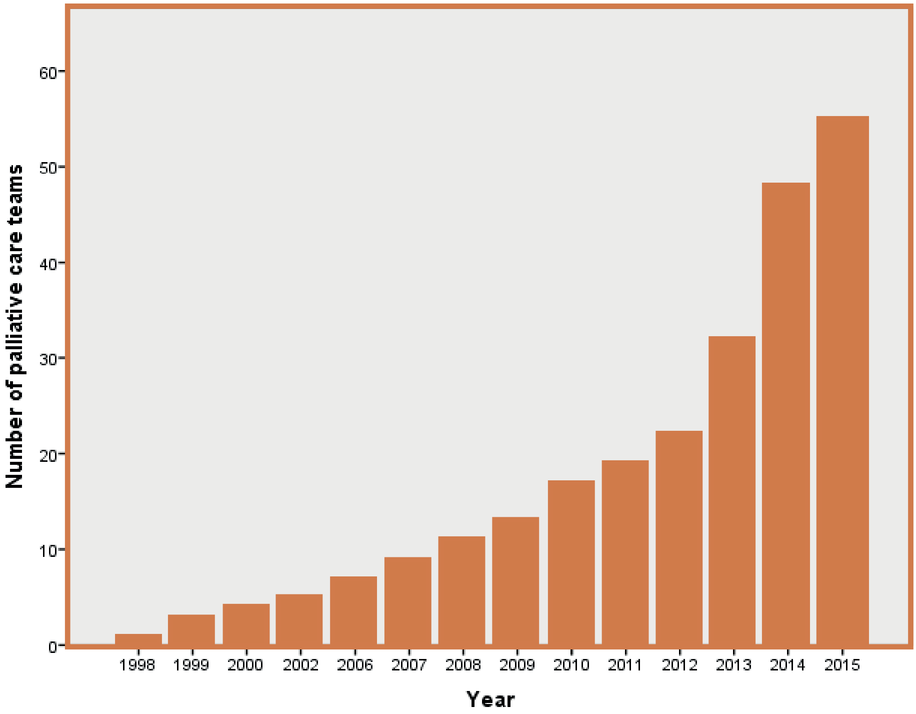
Palliative care is on the agenda of most hospitals (Table 1). The majority of hospitals has an assignment from the board of directors or medical staff to develop palliative care (82%) or has a steering committee implementing palliative care (85%). Fifty-four percent of all hospitals have a palliative care policy of some form. Overall, 77% of hospitals have a SPCT and the other 23% are in the process of starting one. The number of teams has increased rapidly over the last 3 years (Fig. 1). Other palliative care facilities, such as labelled palliative care beds (20%), inpatient units for palliative care (7%), outpatient palliative care clinics (22%) and palliative day-care facilities (4%) are relatively scarce.

Table 1. Hospital characteristics (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 board or medical staff to develop palliative care	61 (82)
Palliative care steering group	63 (85)
Specialist Palliative Care Team	57 (77)
Number of SPCTs that started before 2012	19 (34)
Number of SPCTs that started before 2010	13 (25)
Outpatient palliative care clinic	16 (22)
Palliative daycare	3 (4)
Labelled palliative care beds	15 (20)
Labelled beds palliative care unit	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)

A vast majority of all hospitals uses measurement instruments (90%) 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.

Figure 1. Number of hospitals with a specialist palliative care team (N=55)*



** Starting date was missing for two hospitals*

Specialist palliative care teams

Number of consultations

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

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

SPCTs in university hospitals have more referrals compared to SPCTs in general and teaching hospitals. SPCTs 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 SPCTs can be consulted for inpatients, but only 28 teams provided consultations in the outpatient clinic, with a median annual number of consultations for outpatients of 20 (range 2-384). Ten teams made home visits with a median annual number of 6 consultations (range 1-74). Twenty-four percent of the respondents stated that the number of consultations exceeds their capacity; 47% stated that the number of referrals is less than their capacity; 47 % stated that the number of consultations is less than their capacity. The annual number of inpatient palliative care consultations 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 SPCT

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

Procedures followed by the SPCT

Table 2 describes characteristics of the consultation process followed by the SPCTs. 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 SPCTs is available 24/7. Most consultations involve face to face contact of the SPCT 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 SPCT 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 specialist palliative care team consultation process (N = 57)

	n (%)
The team has specified referral criteria	41 (72)
Who can consult the SPCT?	
Medical specialists	57 (100)
Interns	24 (42)
Paramedics	23 (40)
Nurses	45 (79)
Patients and/or relatives	15 (24)
For which type of patients can the SPCT be consulted?	
Clinical patients	57 (100)
Patients at the outpatient clinic	35 (62)
Patients who are known by the SPCT and who are staying at home	29 (51)
Patients who are not known by the SPCT 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)
Follow up of the patient is standard	
Mostly	28 (49)
Sometimes	26 (46)
Never	3 (5)
Follow up with the referring professional is standard	
Mostly	30 (53)
Sometimes	27 (47)
Deliberation with the transfer nurse about the situation @home is standard	
Yes, always	4 (25)
When indicated	37 (65)
No	6 (11)

Table 2. (Continued)

	n (%)
Deliberation with the general physician – nursing home physician before discharge	
Yes, always	15 (26)
When indicated	30 (53)
No	12 (21)
Members of the SPCT visit patients @home	13 (23)
Forms of outpatient / @home collaboration	
SPCT comprises both hospital & community professionals	31 (54)
SPCT provides telephone consultation for patients outside the hospital	19 (33)
SPCT provides bedside consultation outside the hospital	11 (19)
Regional SPCTs provide in-hospital bedside consultation	5 (9)
SPCT does not work across care settings	13 (23)
Other activities of the SPCT	
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 specialist palliative care team meetings (N = 57)

	n (%)
The frequency of SPCT meetings is at least once a week	54 (95)
The person who requests the consultation is present at the SPCT'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)
The SPCT's advice is sent to the general practitioner / nursing home physician	30 (53)
The SPCT's advice is sent to the person who requested the consultation	43 (75)
SPCT participates in other departments' multidisciplinary team meetings	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 SPCT is the Distress Thermometer (56%).

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

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

	n (%)
The SPCT uses guidelines and measurement instruments	51 (90)
The SPCT has specified quality criteria	37 (65)
The SPCT 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 patient care	
Yes, regularly	27 (46)
Yes, incidentally	29 (51)
No	1 (2)

*Care for carers refers to caring for the healthcare professionals

Supporting and impeding factors for the development and implementation of the SPCT

Respondents were asked to mention factors that either improved or impeded the development and implementation of the team. The most frequently mentioned supportive factors where enthusiasm and motivation of the SPCT members, including a role as 'ambassador' of the team for 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 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 SPCT 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 SPCT (18%) and a (negative) attitude of some medical specialists and nurses towards the SPCT (18%). Some respondents (5%) mentioned late referral to the SPCT 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 SPCT has risen from 39% in 2013 up to 77% in 2015[13] In all likelihood, the norms set by the Dutch Federation of Oncological Societies (SONCOS), which state that each hospital should have a SPCT by January 2017, contributed to the substantial increase in numbers of teams.[12]

As positive as this increase may be, the characteristics of the SPCTs 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 SPCT takes time. In the literature, many barriers to consultation of SPCTs 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 SPCTs are often consulted late in the disease trajectory.[15-19]

In studies that show positive effects of SPCTs, 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, still less than a quarter of hospitals offer their patients this opportunity for early palliative care support.[13]

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. Generalist palliative care professionals in hospitals as well as SPCTs use a wide variety of measurement instruments. In this survey, most commonly used instrument 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 SPCT.[21 22]

In a one-day observational study in 14 Belgian hospitals, it was found that 9.4% of all patients admitted to the hospital are in a palliative care trajectory, which was defined as the trajectory where a patient is suffering from an incurable, progressive, life-threatening disease, without a prospect of remission, stabilisation or improvement.[23] A study by Gardiner et al. in two acute hospitals in the UK showed that 36% of all hospitalised 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 service penetration of 4.4% was found.[26] This implies that more patients in hospitals could benefit from specialist palliative care.

Furthermore, the number of labelled hours that members of the SPCTs have for their work as a specialist palliative care consultant, is very low, especially for physicians. This is in line with a recent report of the Economist Intelligence Unit on the Quality of Death Index. Although 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 (22th). This means that the availability of specialists in palliative care and healthcare professionals with general knowledge of palliative care is low, as is the availability of appropriate training.[27] This is confirmed by the lack of financing of the SPCTs in hospitals in our study.

Dumanovsky et al. conclude that higher staffing levels (full-time equivalents of SPCT members per 10,000 admissions) were associated with higher service penetration (the annual number of specialist palliative care consultations as a percentage of total annual number of hospital admissions). In their study, palliative care programmes with the highest staffing levels ($\geq$ 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 specialist palliative care consultation.[26]

Strengths and limitations

This nationwide study demonstrates the increasing number of SPCTs 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 of) SPCTs. A strength of this study is the relatively high response rate. Among the non-responders were both hospitals with and without SPCTs. Therefore we can conclude that this study gives a good overview of current specialist palliative care practices in Dutch hospitals.

A limitation is that our study does not provide insight in the quality of palliative care in Dutch hospitals or in the quality of the SPCT consultations. From a recent comparison between different countries, using data from 2010, it was found that end-of- life care in the Netherlands is characterised 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 healthcare professionals for 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 SPCTs and to gain more insight in the timing and the quality of specialist palliative care team involvement in Dutch hospitals.

Conclusion

Palliative care in Dutch hospitals is often supported by SPCTs. 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 SPCTs in care for incurably ill patients is relatively limited. To stimulate the further development and implementation of SPCTs in hospitals, we recommend the development of a formalised quality framework with models for (transmural) palliative care team consultation, to improve the quality of palliative care in hospitals. Such a framework, that should be adopted by professional organisations and policymakers, can form the basis for the development of quality criteria and quality assessment of SPCTs. 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 SPCTs is necessary to increase the number of SPCT consultations.

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Competing interests

The authors declare that they have no competing interests.

Consent for publication

Not applicable.

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Supplement

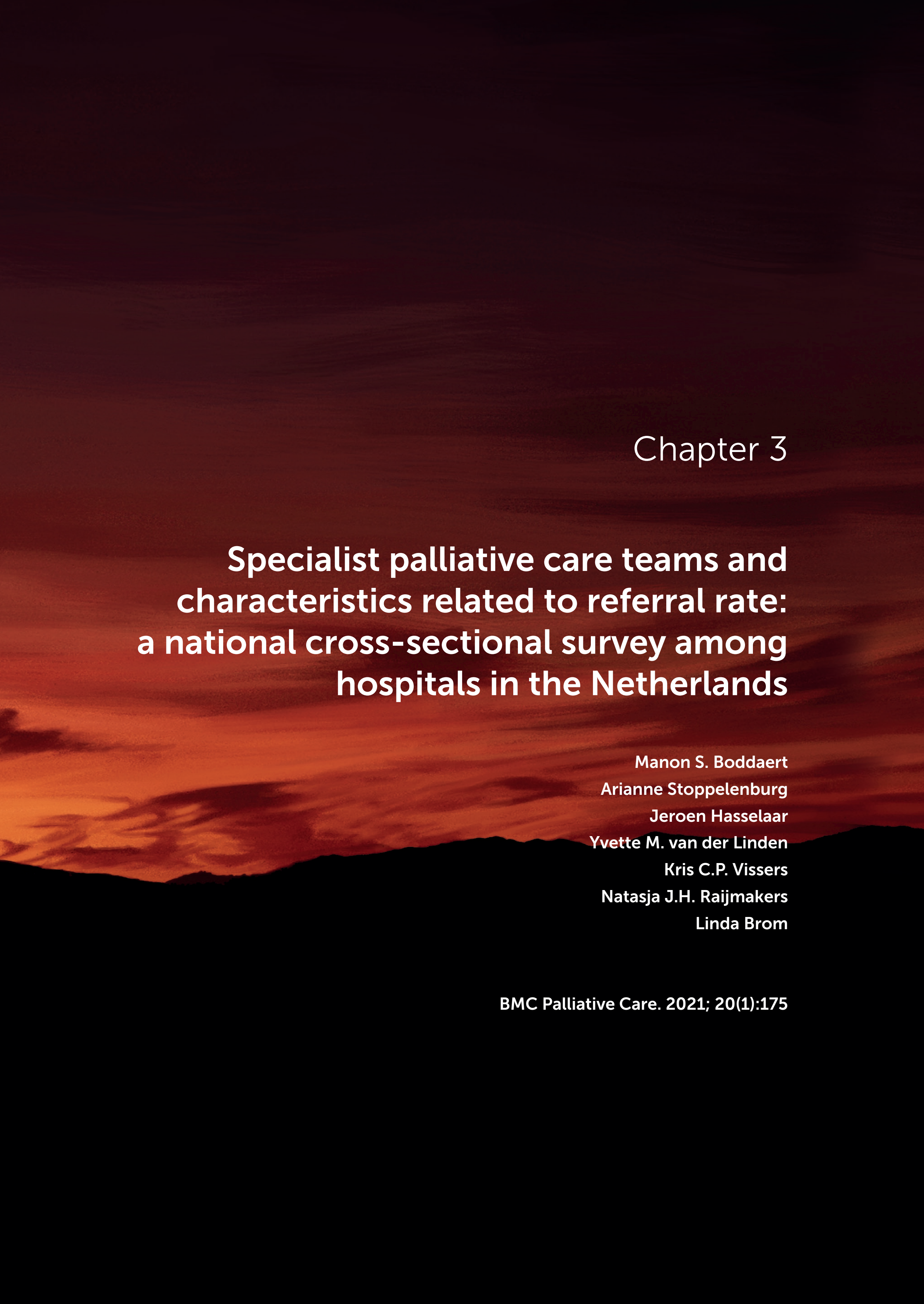
Supplement table. Disciplines represented in the palliative care consultation teams (n=57)

	n (%)	
Nurse*	41 (72)	
Nurses without labelled hours		8 (20)
Nurses with labelled hours		33 (80)
Nurse practitioner	31 (54)	
Nurse practitioners without labelled hours		6 (21)
Nurse practitioners with labelled hours		23 (78)
Anaesthesiologist	44 (77)	
Anaesthesiologists without labelled hours		25 (61)
Anaesthesiologists with labelled hours		16 (39)
Internal medicine specialist	51 (90)	
Internal medicine specialists without labelled hours		29 (62)
Internal medicine specialists with labelled hours		18 (38)
Radiotherapist	15 (26)	
Radiotherapists without labelled hours		11 (85)
Radiotherapists with labelled hours		2 (15)
Lung specialist	33 (58)	
Lung specialists without labelled hours		22 (73)
Lung specialists with labelled hours		8 (27)
Clinical geriatrician	27 (47)	
Clinical geriatricians without labelled hours		14 (63)
Clinical geriatricians with labelled hours		8 (37)
Nursing home physician	18 (32)	
Nursing home physicians without labelled hours		6 (40)
Nursing home physicians with labelled hours		9 (60)
General practitioner	19 (33)	
General practitioners without labelled hours		6 (38)
General practitioners with labelled hours		10 (62)
Spiritual counsellor	37 (65)	
Spiritual counsellors without labelled hours		21 (64)
Spiritual counsellors with labelled hours		12 (36)

Supplement table. *(Continued)*

	n (%)	
Psychologist	16 (28)	
Psychologists without labelled hours		14 (93)
Psychologists with labelled hours		1 (7)
Social worker	17 (28)	
Social workers without labelled hours		14 (82)
Social workers with labelled hours		3 (18)
Mean number of disciplines participating in the teams (sd)	6,5 (2,4)	

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



Chapter 3

Specialist palliative care teams and characteristics related to referral rate: a national cross-sectional survey among hospitals in the Netherlands

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Abstract

Background

Specialist palliative care teams (SPCTs) in hospitals improve quality of life and satisfaction with care for patients with advanced disease. However, referrals to SPCTs are often limited. To identify areas for improvement of SPCTs' service penetration, we explored the characteristics and level of integration of palliative care programmes and SPCTs in Dutch hospitals and we assessed the relation between these characteristics and specialist palliative care referral rates.

Methods

We performed a secondary analysis of a national cross-sectional survey conducted among hospitals in the Netherlands from March through May 2018. For this survey, a previously developed online questionnaire, containing 6 consensus-based integration indicators, was sent to palliative care programme leaders in all 78 hospitals. For referral rate we calculated the number of annual inpatient referrals to the SPCT as a percentage of the number of total annual hospital admissions. Referral rate was dichotomised into high ($\geq$ third quartile) and low (< third quartile). Characteristics of SPCTs with high and low referral rate were compared using univariate analyses. P-values < 0.05 were considered significant.

Results

In total, 63 hospitals (81%) participated in the survey, of which 62 had an operational SPCT. The palliative care programmes of these hospitals consisted of inpatient consultation services (94%), interdisciplinary staffing (61%), outpatient clinics (45%), dedicated acute care beds (21%) and community-based palliative care (27%). The median referral rate was 0.56% (IQR 0.23 – 1.0%), ranging from 0 – 3.7%. Comparing SPCTs with high referral rate ($\geq$1 %, n = 17) and low referral rate (< 1%, n = 45) showed significant differences for SPCTs' years of existence, staffing, their level of education, participation in other departments' team meetings, provision of education and conducting research. With regard to integration, significant differences were found for the presence of outpatient clinics and timing of referrals.

Conclusion

In the Netherlands, palliative care programmes and specialist palliative care teams in hospitals vary in their level of integration and development, with more mature teams showing higher referral rates. Appropriate staffing, dedicated outpatient clinics, education and research appear means to improve service penetration and timing of referral for patients with advanced diseases.

Introduction

Early provision of specialist palliative care for patients with advanced disease or frailty strongly relates to a better quality of life, less depression and anxiety and higher satisfaction with care.[1-6] Moreover, population-based cohort studies across various care settings have also shown better quality of care, defined as less potentially inappropriate healthcare utilisation at the end of life, in patients who received early specialist palliative care.[7-10] Consequently, international guidelines recommend early integration of specialist palliative care and oncology care.[11 12]

Based on international expert consensus, 13 major integration indicators have been developed to assess the level of integration of specialist palliative care and oncology care in hospitals.[13] A survey study using these indicators demonstrated that European Society for Medical Oncology (ESMO) - Designated Centres (DCs) of Integrated Oncology and Palliative Care (PC) had high levels of integration with regard to palliative care programme organisation, but timing of referral and education remained areas for further development.[14]

Among multiple models of palliative care delivery, hospital-based specialist palliative care teams (SPCTs) are one way to promote the integration of patient-directed care and disease-directed treatment.[15-17] As a measure for SPCTs' service penetration, the National Palliative Care Registry in the United States used the number of annual inpatient palliative care consultations as a percentage of the number of total annual hospital admissions to determine referral rate.[18] Over the years they have reported a steadily increasing average referral rate.[19] Moreover, they demonstrated that higher staffing levels of SPCTs were associated with higher referral rates, which were subsequently associated with earlier initial palliative care consultation during hospital admission.[18]

In the Netherlands all healthcare professionals are expected to provide generalist palliative care, informed by national standards and guidelines. Palliative care specialists can be consulted to provide support and expert advice. As such, professional oncology standards, issued by the Dutch Federation of Oncological Societies (SONCOS), state that from 2017 every hospital providing cancer care should have a SPCT available.[20] Staffing of the SPCT should at least consist of 2 medical specialists and a nurse with specific expertise in palliative care. The nurse is preferably an oncology nurse or nurse practitioner in oncology or anaesthesiology/pain medicine. At least one of the medical specialists must have completed specific training in the field of palliative care.

In a three-yearly survey study we routinely monitor the development of SPCTs and explore their characteristics.[21] Although our survey study in 2015 showed an increase in SPCTs in Dutch hospitals, the number of inpatient palliative care referrals was limited (median 77 consultations per year) and the referral rate was low (mean 0.6%) compared to hospitals in the US (mean 4.4%).[18 21] Additionally, we demonstrated a wide variation in

interdisciplinary staffing of SPCTs, level of education and experience.
We conducted a secondary analysis of the survey study in 2018 to specifically explore characteristics and level of integration of palliative care programmes and their SPCTs as well as the relation between these characteristics and high or low specialist palliative care referral rates, to identify areas for improvement of SPCTs' service penetration. We hypothesised that hospital palliative care programmes with high referral rates would be better staffed and better integrated, with earlier timing of referrals.

Methods

Study design

This is a secondary analysis to identify characteristics of hospital palliative care programmes and their SPCTs related to higher referral rates based on the results of a three-yearly cross-sectional survey of SPCTs in all Dutch hospitals, conducted from March through May 2018. The STROBE reporting guideline for cross-sectional studies was used.[22] Results from the primary analysis have been described elsewhere.[23]

Setting and participants

The heads of SPCTs or palliative care programme leaders of all 78 hospitals in the Netherlands were invited to participate in a voluntary online survey. The hospitals consisted of general (n=38), teaching (n=30) and university (n=8) hospitals and dedicated oncology centres (n=2). For the online questionnaire, Survey Monkey was used and to maximize response rate, the participants were sent a reminder after two weeks. No financial incentives were provided.

Questionnaire

For the first survey in 2013, we generated survey questions based on interviews and expert meetings.[24] Subsequently, the questionnaire for the second survey in 2015 was pilot tested by several SPCT members for face validity and readability, and length of the questionnaire.[21] The questionnaire for the survey in 2018 was reviewed and updated to serve the primary aim of this three-yearly survey focused on the development and characteristics of SPCTs in Dutch hospitals. The final version of the (online) questionnaire contained 77 items based on the Donabedian triad of structure, processes and outcomes (Supplement).[25]
The first part of the questionnaire focused on hospital and palliative care programme characteristics, including assignment of executive board, year of start of SPCT, presence of inpatient consultation services, of dedicated outpatient clinics, of dedicated acute

care beds, of community-based palliative care, of triggered referral for specific diagnoses, and timing of referrals. Community-based palliative care was defined as providing bedside consultation at home and having professionals from both hospital and primary care setting on the SPCT.

The second part of the questionnaire assessed SPCT characteristics including staffing, level of education, process of consultation, didactic and research efforts and numbers of consultations in various settings.

With regard to level of education, professional oncology standards recommend that SPCT members are trained in specialist palliative care.[20] As in the Netherlands palliative medicine is not a certified medical or nursing (sub)specialty, the questionnaire listed the available postgraduate palliative care education for both physicians, nurses and nurse practitioners to assess the level of education of SPCT members. This included an 8-day medical course and a 2- year continuing medical education (CME) for physicians, a basic palliative care training and a 1-year continuing nursing education (CNE) for nurses and a differentiation in palliative care for nurse practitioners.

Indicators to assess integration of palliative care in hospital care

To evaluate hospital-wide integration of palliative care we used six indicators from an existing set of 13 major indicators for integration of oncology and palliative care programmes, established through international expert consensus.[13] Our limitation to six indicators was pragmatically based on availability of items in the questionnaire that was developed for the three-yearly survey study. The six indicators available from our survey were: presence of inpatient consultation services, presence of a dedicated outpatient clinic, interdisciplinary staffing of the SPCT (i.e., including at least a physician, nurse and psychosocial team member such as psychologist/counsellor, chaplain, social worker), routine symptom screening of palliative care patients, early referral to SPCT, and presence of a didactic palliative care curriculum. Three indicators were adjusted to the Dutch hospital setting. First, routine symptom screening of palliative care patients was broadened to make it suitable for the evaluation of hospital wide integration of palliative care. We considered the use of a tool for identification of palliative care patients to be similarly suitable as routine symptom screening. Second, early referral to SPCT was defined as a need-based referral > 3 months before death, based on previous literature, as international consensus on the definition of early referral is still lacking.[13 26]

Last, the indicator ‘evaluating availability of a didactic palliative care curriculum for fellows in oncology’ was broadened to the availability of a palliative care curriculum for nurses, interns, residents and/or fellows throughout the hospital.

Statistical analysis

Descriptive statistics were used to summarize characteristics of the hospital palliative care programmes, SPCTs and integration indicators. Hospitals without an operational SPCT were excluded from the analysis. Characteristics of the SPCTs were described for teams with inpatient referrals (i.e.,, referral rate > 0%). As each palliative care programme could score multiple integration indicators, we calculated an integration index. This represents a composite score of the six integration indicators; 1 point was given for each affirmative response. Total score ranges from 0 to 6, with a higher index indicating a greater level of integration.

To assess relations between characteristics and high specialist palliative care referral rates, we determined referral rates by calculating the number of annual inpatient palliative care consultations as a percentage of total annual hospital admissions.[18] We calculated mean, range, median and interquartile range (IQR) of referral rates to detect if results had a skewed distribution. To differentiate between teams with high and low referral rates, we used the IQR and defined referral rate as low for SPCTs with referral rate < third quartile and as high for SPCTs with referral rate ≥ third quartile.

SPCTs with high and low referral rate were compared in univariate analysis using t-test, Chi-square test and Fisher exact test. Missing data >5% were reported. All analyses were two-sided and p values <0.05 were considered significant. All analyses were conducted using STATA version 16.1 (StataCorp LLC, Texas, USA).

To evaluate representability of our study population, all non-responding hospitals were contacted after the survey closed to verify hospital type, presence of an operational SPCT and certification as ESMO-DC of integrated oncology and PC.

Results

In all, 63 out of 78 Dutch hospitals participated, resulting in a response rate of 81%. Respondents consisted of 27 general hospitals, 26 teaching hospitals, eight university hospitals and two dedicated oncology centres. All but one general hospital had an operational SPCT and thus 52 non-tertiary (general and teaching hospitals) and 10 tertiary hospitals (university hospitals and dedicated oncology centres) were included for analysis (Table 1).

Non-responding hospitals consisted of 11 general hospitals and 4 teaching hospitals, of which one was certified as ESMO-DC of integrated oncology and PC. All non-responding hospitals had an operational SPCT.

Hospital and palliative care programme characteristics

In total, 94% (n=58) of all 62 hospitals provided inpatient palliative care (PC) consultation services, 45% (n=28) offered dedicated outpatient clinics, 21% had dedicated acute care beds present and 27% (n=17) provided community-based palliative care (Table 1). Most palliative care programmes had an assignment of the executive board (60%, n=37) and most SPCTs had been operational for over 3 years (61%, n=38). Thirteen hospitals (21%) were certified as an ESMO-DC of integrated oncology and PC. Additionally, more than half of the hospitals (58%, n=36) routinely used a tool to identify palliative care patients. In 31% (n=19) referrals mostly occurred in the last 4 days to 2 weeks before death and in 31% (n=19) referrals mostly took place in the last 4 weeks to 3 months before death. Triggered referrals for specific diagnoses occurred in 19% (n=12) of the palliative care programmes.

Hospital and palliative care programme characteristics stratified by referral rate

Referral rates to specialist palliative care ranged from 0 – 3.7% with a mean of 0.85%, a median of 0.56% and an IQR between 0.23 – 1.0%. Defined by a cut-off at the third quartile, 45 hospital palliative care programmes had a low (< 1%) and 17 had a high referral rate (≥ 1%). In palliative care programmes with high referral rates, SPCTs more often existed longer than three years compared to SPCTs in programmes with low referral rates (82% vs 53%; p=0.04) (Table 1) and dedicated outpatient clinics were present more often (76% vs 33%; p=0.004). Timing of referral also differed: in high referral rate programmes most patients were referred between 4 weeks to 3 months before death (71%), while in low referral rate programmes referrals mostly occurred in the last 4 days to 2 weeks before death (40%) (p < 0.001).

Table 1. Characteristics of hospitals and their palliative care programme stratified by referral rate*

	Total (n=62)	Low referral rate (LRR)* (n=45)	High referral rate*(HRR) (n=17)	p-value
Number of hospital admissions /year *(mean, SD)*	23.622 (11.856)	23.813 (12.626)	23.116 (9.853)	.84
	N (%)	N (%)	N (%)	
Type of hospital				.33
Tertiary	10 (16)	6 (13)	4 (24)	
Non-tertiary	52 (84)	39 (87)	13 (76)	
ESMO-DC of integrated oncology and PC	13 (21)	8 (18)	5 (29)	.32
PC assignment of the hospital executive board	37 (60)	27 (60)	10 (59)	.93
Existence of specialist palliative care team*				**.04**
≤ 3 years	24 (39)	21 (47)	3 (18)	
>3 years	38 (61)	24 (53)	14 (82)	
Presence of inpatient PC consultation services	58 (94)	41 (91)	17 (100)	.57
Presence of dedicated PC outpatient clinic	28 (45)	15 (33)	13 (76)	**.004**
Presence of dedicated acute care beds	13 (21)	10 (22)	3 (18)	1.00
Presence of physical dedicated PC unit (n=13)	6 (46)	5 (50)	1 (33)	.61
Provision of community-based palliative care*	17 (27)	10 (22)	7 (41)	.14
Routine identification of PC patients[7]	36 (58)	22 (51)	13 (76)	.09

Table 1. (Continued)

	Total (n=62)	LRR (n=45)	HRR (n=17)	p-value
Triggered referral for specific diagnoses	12 (19)	8 (18)	4 (24)	.72
Average timing of referral prior to death				**< .001**
< 3 days	5 (8)	5 (11)	0	
4 days – 2 wks	19 (31)	18 (40)	1 (6)	
2 wks – 4 wks	10 (16)	9 (20)	1 (6)	
4 wks- 3 months	19 (31)	7 (16)	12 (71)	
>3 months	2 (3)	2 (4)	0	
Unknown	7 (11)	4 (9)	3 (18)	

***** Referral rate: Nº of annual inpatient referrals / Nº of total annual hospital admissions x 100. Low referral rate < 1% (third quartile), high referral rate ≥ 1%. **α**: The cut off at 3 years existence was based on previous research of Brinkman et al. showing a difference in referral rate between SPCTs younger and older than three years.[21] **β:** Community-based palliative care defined as providing bedside consultation at home and having professionals from both hospital and primary care setting on the SPCT. **γ**: use of tool for identification of palliative care patients.

Specialist palliative care team characteristics

In total, 58 SPCTs had inpatient consultation services and their characteristics are presented below. Four teams had no inpatient palliative care referrals (referral rate was 0%), they had been operational for less than 3 years.

On average these 58 SPCTs were staffed with 4.3 (SD 2.4) physicians and 2.3 (SD 2.4) nurses and they had a mean of respectively 13.2 (SD 16.4) and 35.8 (SD 27.9) designated hours per week to participate in their SPCT (Table 2). Of all 58 SPCTs, 36 had designated hours for a psychologist / counsellor, chaplain or social worker (mean designated hours was 1.2 (SD 3.0)). Two thirds of SPCTs had at least one physician with a 2-year PC continuing medical education (CME) (67%, n=39), nurse with a 1-year PC continuing nursing education (CNE) (66%, n=38) or nurse practitioner (71%, n=41) on their team.

Additionally, 38% (n=22) of SPCTs employed nurses with basic palliative care training. Half of all SPCTs (52%, n=30) participated in other departments' multidisciplinary team meetings (MDTMs) and 17% (n=10) of SPCTs were available outside office hours.

Most SPCTs provided nurse-based initial consultation (62%, n=36). Overall, SPCTs had a mean annual number of inpatient referrals of 202 (SD 177). For 35 SPCTs providing outpatient care the mean number of outpatient referrals was 65 (SD 96). Of all SPCTs 17 provided consultations in the community, with a mean of 12 (SD 18) visits per year. The largest group of SPCTs (47%, n=27) indicated that the proportion of non-oncology referrals was between 20 - 40%.

Almost all SPCTs (98%, n=57) provided education within their own hospital and 71% (n=41) provided education outside their own hospital. Over one third of all SPCTs participated in research (38%, n=22).

Specialist palliative care team characteristics stratified by referral rate

Of all 58 SPCTs, 41 had a low referral rate and 17 had a high referral rate.

High referral rate SPCTs had more designated hours per week for both physicians (22.8 vs 9.2; p=0.003) and nurses (51.5 vs 29.3; p=0.004) compared to low referral rate SPCTs (Table 2). Also, high referral rate SPCTs employed more nurses with a 1-year PC CNE compared to low referral rate SPCTs (2.4 vs 1.2; p=0.022), whereas low referral rate SPCTs more often included nurses with basic PC training compared to high referral rate SPCTs, respectively 49% vs. 12% (p=0.009).

High referral rate SPCTs more often participated in multidisciplinary team meetings than low referral rate SPCTs (76% vs 41%; p=0.021).

The mean number of annual inpatient referrals was 114 (SD 78) for low referral rate SPCTs and 417 (SD 168) for high referral rate SPCTs. Similarly, SPCTs with low referral rate provided less outpatient consultations than SPCTs with high referral rate, respectively 29 (SD 55) vs 120 (SD 119) (p=0.004). Education outside their own hospital was provided by all high referral rate SPCTs and by 59% of low referral rate SPCTs (p=0.001). Also participation in research differed between teams with high and low referral rates, respectively 65% and 27% (p=0.016).

Table 2. Characteristics of specialist palliative care teams stratified by referral rate*

	Total	**Low referral rate*(LRR)**	**High referral rate*(HRR)**	**p-value**
	(n=58)	**(n=41)**	**(n=17)**	
	Mean (SD)	**Mean (SD)**	**Mean (SD)**	
Nº of inpatient referrals	202 (177)	114 (78)	417 (168)	
Nº of outpatient referrals (n=35$^{\$}$)	65 (96)	29 (55)	120 (119)	**.004**
Nº of community visits (n=17)	12 (18)	6 (12)	23 (24)	.06
SPCT Staffing				
Nº of physicians in team	4.3 (2.4)	4.3 (2.4)	4.5 (2.5)	.71
Nº of nurses in team	2.3 (2.4)	2.2 (2.3)	2.7 (2.6)	.44
Nº of designated PC hours / w (physicians)	13.2 (16.4)	9.2 (12.3)	22.8 (20.9)	**.003**
Nº of designated PC hours / w (nurses)	35.8 (27.9)	29.3 (24.9)	51.5 (29.3)	**.004**
Nº of design. PC hours / w (psychosocial)$^{\#}$ (n=36)	1.2 (3.0)	1.0. (2.5)	2.3 (4.5)	.29

	Total	LRR (n=41)	HRR (n=17)	p-value
N° of team members with specific training				
*# physicians with 2-year palliative care CME***	1.3 (1.3)	1.1 (1.1)	1.7 (1.7)	.12
# physicians with 8-day course in palliative care	2.5 (2.2)	2.5 (2.0)	2.7 (2.6)	.70
*# nurses with 1-year palliative care CNE****	1.6 (1.8)	1.2 (1.6)	2.4 (2.1)	**.022**
# nurses with basic PC training	0.7 (1.4)	0.9 (1.5)	0.3 (1.0)	. 12
# nurse practitioners	1.5 (1.4)	1.3 (1.4)	1.9 (1.5)	.17
	N (%)	N (%)	N (%)	
Level of education present in team				
*Physician(s) with 2-year palliative care CME***	39 (67)	26 (63)	13 (76)	.38
Physician(s) with 8-day course in palliative care	58 (100)	41 (100)	17 (100)	1.00
*Nurses with 1-year palliative care CNE****	38 (66)	25 (61)	13 (76)	.37
Nurses with basic PC training	22 (38)	20 (49)	2 (12)	**.009**
Nurse practitioners in PC	41 (71)	27 (66)	14 (82)	.34
Participation in other departments' MDTMs[$$]	30 (52)	17 (41)	13 (76)	**.021**
Availability outside office hours	10 (17)	7 (20)	2 (12)	.79
Initial consultation				.69
Nurse-based	36 (62)	24 (59)	12 (71)	
Physician-based	21 (36)	16 (39)	5 (29)	
Unknown	1 (2)	1 (2)	-	
Proportion of non-oncology referrals				.20
< 20%	14 (24)	11 (27)	3 (18)	
20-40%	27 (47)	15 (37)	12 (71)	
40-60%	13 (22)	11 (27)	2 (12)	
60-80%	3 (5)	3 (7)	0	
>80%	1 (2)	1 (2)	0	
Non-clinical activities				
Education inside own hospital	57 (98)	40 (98)	17 (100)	1.00
Education outside own hospital	41 (71)	24 (59)	17 (100)	**.001**
Research	22 (38)	11 (27)	11 (65)	**.016**

* Referral rate: N° of inpatient referrals / N° of hospital admissions x 100. Low referral rate < 1% (third quartile), high referral rate ≥ 1%. [$] Not all SPCTs had a dedicated outpatient clinic, while providing out-patient consultations; [$$] MDTM: Multidisciplinary team meeting ** CME: Continuing medical education; *** CNE: Continuing nursing education. [#] Psychologist / counsellor, chaplain, social worker.

Level of hospital-wide integration of specialist palliative care

Evaluation of hospital-wide integration of specialist palliative care programmes by use of the six integration indicators, showed that 94% (n=58) of all 62 hospitals provided inpatient consultation services, 45% (n=28) had outpatient clinics and 61% (n=38) had interdisciplinary staffing of the SPCTs. Also, more than half of the hospitals (58%, n=36) routinely used a tool to identify palliative care patients, 3% (n=2) on average referred patients to SPCTs more than three months before their death and most hospitals (95%, n=59) had a didactic palliative care curriculum (Table 3). The integration index resulted in a higher, near significant level of integration for high referral rate palliative care programmes compared to low referral rate programmes (3.42 vs 3.94; p=0.06).

Table 3. Level of hospital-wide integration of specialist palliative care (adapted from Hui et al. 2015)

	Total (n=62)	**Low referral rate* (n=45)**	**High referral rate* (n=17)**	**p-value**
Integration indicators	**N (%)**	**N (%)**	**N (%)**	
Presence of inpatient PC consultation services	58 (94)	41 (91)	17 (100)	.57
Presence of dedicated PC outpatient clinic	28 (45)	15 (33)	13 (76)	**.004**
Presence of interdisciplinary SPCT β	38 (61)	31 (69)	7 (41)	.08
Routine identification of PC patients α	36 (58)	22 (51)	13 (76)	.09
Early referral to PC (≥ 3 months)	2 (3)	2 (4)	0 (0)	1.0
*Presence of didactic palliative care curriculum***	59 (95)	42 (93)	17 (100)	.56
Integration index# *(Mean, SD)*	3.6 (.93)	3.4 (.97)	3.9 (.90)	.06

* Referral rate: N° of annual inpatient referrals / N° of total annual hospital admissions x 100. Low referral rate < 1%, high referral rate ≥ 1%. β: team of a physician, a nurse and a psychosocial team member (psychologist / counsellor, chaplain, social worker); α: assessment tools for identification of palliative care phase. ** Education provided to nurses, interns, residents and / or fellows hospital-wide. # This represents a composite score of 6 integration indicators; 1 point was given for each affirmative response. Total score ranges from 0 to 6, with a higher index indicating a greater level of integration.

Discussion

This cross-sectional survey shows that the palliative care programmes of almost all hospitals in the Netherlands consist of SPCTs providing inpatient consultation services. Moreover, nearly two third of these SPCTs are interdisciplinary staffed, half of the programmes provide outpatient clinics and a substantial part has dedicated acute care beds and provides community-based palliative care. However, the median referral rate is limited to 0.56% of total annual hospital admissions and referral to these SPCTs

occurs late in the disease trajectory.
SPCTs with a high referral rate seem to be more mature than low referral rate SPCTs as the latter frequently have a shorter time of existence and limited staffing with a more basic level of education. In addition, high referral rate SPCTs appear to be better integrated as they are more often related to presence of dedicated outpatient clinics and subsequent earlier timing of referrals, more frequently participate in other departments' multidisciplinary team meetings and in research, and more often provide education outside their own hospital.

Overall, our three-yearly surveys show that the number of Dutch hospitals providing a SPCT with inpatient consultation services has grown steadily from 39% in 2013, 77% in 2015 to 94% in 2018.[21 27] A similar, more gradual pattern exists in the development of dedicated outpatient clinics; 11% of hospitals in 2013, 22% in 2015 and 45% in 2018.[21 27] This swift development of palliative care programmes appears a direct result of national professional oncology standards, issued in 2014 and stating that in 2017 a SPCT should be available in every hospital providing cancer care.[20]
Despite these developments, clearly there are areas for improvement. A one-day observational study in 14 Belgian hospitals has previously demonstrated that almost 10% of the admitted population were patients in a palliative care trajectory and one third of them had a life expectancy shorter than 3 months.[28] Moreover, in high income countries it has been estimated that 30-45% of palliative care needs may require specialist palliative care.[29-31] These data seem to indicate that hospital referral rates to specialist palliative care could be expected to approximate 3-4%. This indication is supported by results from the National Palliative Care Registry in the United States (US) demonstrating a steadily increasing overall referral rate from 2.5% in 2008 to 5.3% in 2017.[19] In comparison, although the mean specialist palliative care referral rate in Dutch hospitals increased from 0.6% in 2015 to 0.85% in 2018,[21] service penetration for patients in a palliative care trajectory appears low.

Comparing the integration indicators from our study to a similar survey among 152 ESMO-DCs of integrated Oncology and PC across the world,[14] shows that results for presence of inpatient consultation services are alike, respectively 94% and 90%. Results differ for the presence of outpatient PC clinics (45% vs. 89%), interdisciplinary staffing (61% vs 95%), and didactic palliative care curriculum (95% vs 52%). Regarding timing of referral, most referrals in this ESMO survey occurred between 40-150 days before death for outpatients and between 14–45 days for inpatients, whereas only three percent of our hospitals refer most patients with specialist palliative care needs earlier than 90 days before death. The authors concluded that ESMO-DCs of Integrated Oncology and PC had high levels of palliative care programme organisation, but clinical processes related to timing of referral and education remained areas for further development.[14 32] From our results inpatient consultation services, interdisciplinary staffing and didactic palliative care curricula seem well embedded in most hospital palliative care programmes. However, provision of outpatient clinics and timing of referral seem to warrant further development.

Considering how to improve referral rate and timing of referral, our study shows that high referral rates were related to staffing of SPCTs and their level of education. This finding is in line with other international studies. A survey focusing on integration of palliative care and oncology among 183 institutions across the world noted that a lack of adequately trained palliative care physicians and nurses was one of the most common barriers to palliative care access and development.[33] The previously mentioned ESMO survey underlined this notion by showing that a higher level of education of SPCTs improved integration between specialist palliative care and oncology.[14] Moreover, the US Palliative Care Registry demonstrated increased referral rates were associated with higher staffing levels, which were subsequently associated with earlier initial palliative care consultation during hospital admission.[18]

In addition, our results show that high referral rate SPCTs provided dedicated outpatient clinics significantly more frequently than low referral rate SPCTs and their referrals occurred earlier in the disease trajectory. A recent population-based study in the Netherlands showed that patients provided with palliative care more than 30 days before death were 5 times less likely to experience potentially inappropriate end-of-life care than those with palliative care in the last 30 days or not at all.[9] From our results for timing of referrals it would therefore appear that high referral rate SPCTs may provide better quality of end-of-life care than low referral rate SPCTs.

Multiple randomised controlled trials have demonstrated a positive impact of specialist palliative care on quality of life and quality of end-of-life care when provided in outpatient settings rather than inpatient settings.[26 34] and when provided early and systematically.[1 2 5 35] Moreover, formal screening criteria or palliative care triggers supporting generalist palliative care professionals to select patients for referral, were significantly associated with higher referral rates.[19] Late referrals or a wish to increase referrals were the most commonly cited reasons for implementation.[36]

Based on international literature we hypothesised that hospital palliative care programmes with high referral rates would be better staffed and better integrated, with earlier timing of referrals.

Using referral rate and 6 integration indicators our hypothesis was confirmed with regard to staffing and timing of referral and nearly confirmed with regard to level of integration. Moreover, analysing the characteristics related to high referral rate and integration enabled us to identify areas that could improve availability and accessibility to specialist palliative care.

Based on these results we consider referral rate and integration indicators to be useful assets for our next survey.

Strengths and limitations

This nationwide survey provides a unique insight into the development of SPCTs in Dutch hospitals and characteristics associated with high referral rate. A strength of this study is the high response rate (81%) and the non-responders information indicating that the non-responders had similar characteristics with regard to hospital type, ESMO-DC certification and presence of an operational SPCT. Therefore selection bias is unlikely to have occurred and our findings seem generalizable to all Dutch hospitals. However, some limitations need mentioning.

Although referral rate is an objective measure of accessibility and availability of specialist palliative care and our results are in line with international studies, (trends in) referral rates must be interpreted cautiously. They are likely to be influenced by differences in patient populations (i.e., case-mix) and changes in characteristics of the hospital population over time such as age, disease burden or patterns of diagnoses.[37 38] Ideally, when comparing referral rates, these factors should be taken into account.

The use of international integration indicators made it possible to compare our results to international research. In addition, it enabled us to compare integration of palliative care programmes with high referral rate SPCTs and low referral rate SPCTs. However, not all major integration indicators were available from our data and some indicators had to be adjusted. For future reference our survey for hospital palliative care programmes may be more specifically tuned to the 13 major integration indicators suggested in the literature to fully assess their usefulness for evaluation of hospital-wide integration of specialist palliative care programmes.[13]

A final limitation of this study is the self-reporting nature of the questionnaire. Not all data were necessarily quantified on a patient-level as not all SPCTs register all requested information from their consultations. This may potentially have led to reporting bias. Quantifying data of SPCTs and assessing their impact on quality indicators for end-of-life care in the Netherlands is currently subject of further research.[39 40]

Conclusion and policy implications

Almost all hospitals in the Netherlands have a palliative care programme with a specialist palliative care team. While they have varying levels of integration and development, and more mature teams show higher referral rates, referral of patients with specialist palliative care needs mostly occurs too little and frequently too late. To improve availability of specialist palliative care for support of patients and generalist palliative care professionals, hospitals may consider appropriately staffing and training their SPCTs and implementing palliative care triggers for referral. Adding dedicated outpatient clinics to inpatient consultation services can contribute to early accessibility of SPCTs. On a smaller scale, SPCTs may consider participation in other departments' multidisciplinary team meetings, education in the community and participation in research to increase their service penetration. To support this development on a national level, extending professional oncology standards with these recommendations may prove to be a strong incentive.

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Competing interests

The authors declare that they have no competing interests.

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Supplement

Specialist palliative care teams (SPCT) in hospitals, national survey questionnaire – 2018

Netherlands Comprehensive Cancer Organisation (IKNL), Utrecht, Netherlands & Erasmus MC, University Medical Center Rotterdam, Department of Public Health, Rotterdam, the Netherlands

I. General questions regarding characteristics and organisation of palliative care in your hospital

1. What is the name of the hospital?
2. What is your position within the hospital?
3. What was the total number of hospital admissions in 2017?
   ○ Total number of hospital admissions:...
4. Type of hospital
   ○ General hospital
   ○ Teaching hospital
   ○ University hospital
   ○ Oncological centre
5. Was a specialist palliative care team operational in the hospital in 2017?
   ○ Yes
   ○ No
   ○ No, specialist palliative care team is still in formation.
   ○ Expected date of start:... *(dd/mo/yy)*
6. Is there an outpatient clinic for palliative care?
   ○ Yes
   ○ No
7. Is there a daycare unit for palliative care?
   ○ Yes
   ○ No
8. Are there labeled beds for palliative care?
   ○ Yes
   ○ No
9. Are the labeled beds concentrated on a designated palliative care unit?
   ○ Yes
   ○ No
10. Are there wards with nurses that have palliative care as their special field of interest and education?
   ○ Yes
   ○ No
11. Which wards work with nurses that have palliative care as their special field of interest and education?
   ○ Cardiology
   ○ Dermatology
   ○ Ear, Nose, Throat
   ○ Emergency Department
   ○ Endocrinology
   ○ GI- diseases
   ○ ICU
   ○ Internal diseases
   ○ Neonatal care
   ○ Neurology
   ○ Neurosurgery
   ○ Nephrology
   ○ Pediatrics
   ○ Psychiatrics
   ○ Pulmonary diseases
   ○ Rehabilitation
   ○ Rheumatology
   ○ Surgery

○ Geriatrics
○ Gynecology
○ Hematology
○ Oncology
○ Ophthalmology
○ Orthopedic Surgery
○ Urology
○ Other, namely:...

12. What is the hospital's policy with regard to palliative care? (multiple answers possible)
○ No policy
○ Assignment from the board of directors or medical staff to develop palliative care
○ Palliative care programme / specialist palliative care team with its own multi-year strategy
○ Palliative care integrated in the hospital's multi-year strategy
○ A palliative care committee or steering group
○ A palliative care faculty
○ Other, namely:...

13. Next to the specialist palliative care team, is there a separate pain team operational?
○ Yes
○ No

14. Are tools / measurement instruments being used within the hospital for identification of palliative care patients?
○ Yes
○ No

15. What tools / measurement instruments are used to identify palliative care patients?
○ SPICT (Supportive and Palliative care IndiCators Tool)
○ RADPAC (RADboud indicators for PAlliative Care needs)
○ Surprise Question
○ Other, namely:...

II. General questions regarding characteristics and organisation of the specialist palliative care team (SPCT)

16. What is your position within the SPCT?
○ Head of SPCT / Palliative care programme leader
○ Team member
○ Other, namely:...

17. When did the team start? (dd/mo/yy)

18. What was the number of inpatient consultations for the SPCT in 2017?
○ N.a.; SPCT does not provide inpatient consultation services
○ Number of inpatient consultations: ...

19. What was the number of outpatient consultations for the SPCT in 2017?
○ N.a.; SPCT does not provide outpatient consultation services
○ Number of outpatient consultations: ...

20. What was the number of home visits of the SPCT in 2017?
○ N.a.; SPCT does not provide home visits
○ Number of home visits: ...

21. Which disciplines are represented in the SPCT ? (multiple answers possible)
○ General practitioner
○ Nursing home physician
○ Anesthesiology
○ Internal diseases (oncology)
○ Gastro-enterology
○ Radiotherapy
○ Rehabilitation
○ Nurse practitioner
○ Oncology nurse
○ Pain nurse
○ Pharmacy
○ Psychiatry
○ Psychology
○ Social worker
○ Occupational therapy

○ Geriatrics
○ Pediatrics
○ Pulmonary diseases
○ Neurology
○ Other, namely:...
○ Community nurse
○ Hospital nurse
○ Transfer nurse
○ Other nurse
○ Physical therapy
○ Chaplains
○ Dietician
○ Secretary

22. Which discipline / specialty is head / coordinator of the SPCT? (multiple answers possible)

○ General practitioner
○ Nursing home physician
○ Anesthesiology
○ Internal diseases (oncology)
○ Gastro-enterology
○ Geriatrics
○ Pediatrics
○ Pulmonary diseases
○ Neurology
○ Other, namely:...
○ Radiotherapy
○ Rehabilitation
○ Nurse practitioner
○ Oncology nurse
○ Pain nurse
○ Community nurse
○ Hospital nurse
○ Transfer nurse
○ Other nurse
○ Pharmacy
○ Psychiatry
○ Psychology
○ Social worker
○ Occupational therapy
○ Physical therapy
○ Chaplains
○ Dietician
○ Secretary

23. Which disciplines are not represented on the SPCT but are closely affiliated for consultation? (multiple answers possible)

○ Internal diseases (oncology)
○ Anesthesiology
○ Neurology
○ Pulmonary diseases
○ Radiotherapy
○ Gastro-enterology
○ Pharmacy
○ Psychology
○ Psychiatry
○ Chaplains
○ Social worker
○ Other, namely:...

24. For each SPCT member please indicate discipline / medical specialty and the number of labelled hours per week. In addition, specify the extra efforts (in hours) for the SPCT, if applicable. (The online questionnaire allowed multiple entries per discipline)

	Labelled hours / week	Average extra hours /week
○ General practitioner	○	○
○ Nursing home physician	○	○
○ Anesthesiology	○	○
○ Internal diseases (oncology)	○	○
○ Gastro-enterology	○	○
○ Geriatrics	○	○
○ Pediatrics	○	○
○ Pulmonary diseases	○	○
○ Neurology	○	○
○ Radiotherapy	○	○
○ Rehabilitation	○	○
○ Nurse practitioner	○	○

○ Oncology nurse	○	○
○ Pain nurse	○	○
○ Community nurse	○	○
○ Hospital nurse	○	○
○ Transfer nurse	○	○
○ Other nurse	○	○
○ Pharmacy	○	○
○ Psychiatry	○	○
○ Psychology	○	○
○ Social worker	○	○
○ Occupational therapy	○	○
○ Physical therapy	○	○
○ Chaplains / spiritual caregivers	○	○
○ Dietician	○	○
○ Secretary	○	○
○ Other, namely...	○	○

III. Questions regarding financing of the SPCT

25. How is the SPCT financed? (multiple answers possible)
    - ○ From patients' DBC (Diagnosis-Treatment Combination) palliative care (health insurance)
    - ○ Own financial means from the hospital
    - ○ Otherwise, namely:
26. Which medical specialty can initiate a DBC palliative care? (multiple answers possible)
    - ○ Anesthesiology
    - ○ Internal diseases (oncology)
    - ○ Geriatrics
    - ○ Pulmonary diseases
    - ○ Neurology
    - ○ Pediatrics
27. Are SPCT consultations registered?
    - ○ Yes
    - ○ No
28. Are registered SPCT consultations billed to patients' health insurances?
    - ○ <20% of registered consultations is billed
    - ○ 20-40% of registered consultations is billed
    - ○ 40-60% of registered consultations is billed
    - ○ 60-80% of registered consultations is billed
    - ○ > 80% of registered consultations is billed
    - ○ No, registered consultations are not billed, because...

29. Are there any contracts with health insurance companies about reimbursement?
○ Yes
○ No
30. Are there internal agreements about reimbursement of the SPCT with the board / medical staff?
○ Yes
○ No
31. Was the number of consultations in 2017 in accordance with the number of labeled hours for the members of the SPCT?
○ No, our SPCT actually had too many consultations
○ No, our SPCT actually had too few consultations
○ Yes, the number of consultations was in line with the number of labeled hours

<u>IV. Questions regarding procedures followed by the SPCT</u>

32. Who can request consultation from the SPCT?
○ Medical specialist
○ Resident
○ Intern
○ General practitioner
○ Pharmacist
○ Nurse
○ Paramedics
○ Patient / family
○ Primary healthcare professionals
○ Other, namely...
33. Are there triggered referrals to the SPCT for patients with specific diagnoses?
○ No
○ Yes, namely...
34. What is the average life expectancy for patients referred to the SPCT?
○ 3 days or less
○ 4 days – 2 weeks
○ 2 – 4 weeks
○ 4 weeks – 3 months
○ 3 months or more
○ Unknown
35. For which type of patients can the SPCT be consulted? (multiple answers possible)
○ Inpatients
○ Outpatients
○ Patients who live at home (or elsewhere) and are known to the SPCT
○ Patients who live at home (or elsewhere) and are not necessarily known to the ○ SPCT
○ Others, namely:
36. How does the request for consultation reach the SPCT? (multiple answers possible)
○ By phone
○ Via the electronic patient record
○ Via a paper referral form
○ Via the multidisciplinary team meeting
○ Otherwise, namely:
37. Which types of consultation are provided to patients? (multiple answers possible)
○ By telephone
○ Bedside (inpatient)

○ Face to face (outpatient)
○ Home visit
○ Screen tot screen
○ By e-mail
○ Otherwise, namely:...

38. Which types of consultation are provided **to professionals**? (multiple answers possible)

○ By telephone
○ Face to face
○ Screen tot screen
○ By e-mail
○ Otherwise, namely:...

39. How is the referring professional provided with the SPCT's advice? (multiple answers possible)

○ By telephone
○ Face to face with referring professional
○ Screen tot screen with referring professional
○ In the electronic patient record
○ In the paper patient file
○ On the paper referral form
○ Otherwise, namely:...

40. Where is the consultation documented? (multiple answers possible)

○ In the electronic patient record
○ In the paper patient file
○ In the SPCT's own patient database
○ In the patient's individual care plan
○ Otherwise, namely:...

41. At what times can the SPCT be consulted?

○ 24 / 7
○ Within office hours
○ Otherwise, namely:

42. Is consultation available outside office hours?

○ Yes, through SPCT medical specialist on call
○ Yes, via answering machine / e-mail
○ Yes, through a regional SPCT helpdesk (by phone)
○ Yes, through supraregional SPCT cooperation
○ No, consultation outside office hours is not availble
○ Otherwise, namely:...

43. How much time is available for the initial (first) consultation (in minutes)?

....

44. How much time is available for follow-up consultation (in minutes)?

....

45. **As a rule**, is the patient seen by one or more members of the SPCT?

○ No, usually the consultation is done by telephone with the referring professional
○ As a rule, the patient is seen by a nurse practitioner
○ As a rule, the patient is seen by a nurse
○ As a rule, the patient is seen by a physician
○ As a rule, the patient is seen by a nurse practitioner **and** a physician

○ As a rule, the patient is seen by a nurse **and** a physician
○ As a rule, the patient is seen by a nurse practitioner **or** a physician
○ As a rule, the patient is seen by a nurse **or** a physician
○ As a rule, the patient is seen by a nurse **or** nurse practitioner
○ Otherwise, namely:...

46. What is the average number of contacts of the SPCT with the patient?
○ Only once (initial visit)
○ Daily SPCT visits during hospital admission
○ Otherwise, namely:...

47. What are reasons for referral to the SPCT? (Rank the list from highest to lowest frequency)
○ Explaining illness and prognosis / prognostic awareness
○ Problems / symptoms within the physical domain
○ Problems / symptoms within the psychological domain
○ Problems / symptoms within the social domain
○ Problems / symptoms within the spiritual / existential domain
○ Weighing treatment options
○ Coping of patient and / or family
○ Advance care planning
○ Referral
○ Palliative sedation
○ Euthanasia

48. Are there other reasons for referral to the SPCT?
○ Yes, namely:...

49. Which of the following measurement instruments / tools are used in daily practice? (multiple answers possible)

○ Karnofsky Performance Status (KPS)
○ Palliative Performance Status (PPS)
○ Eastern Cooperative Oncology Group Performance Status (ECOG)
○ Medical Research Council (MRC) Dyspnea
○ Clinical COPD Questionnaire (CCQ)
○ Mouth status screening list
○ Oral Mucositis Assessment Scale (OMAS)
○ Mini-Nutritional Assessment-Short Form (MNA SF)
○ Short Nutritional Assessment Questionnaire (SNAQ)
○ Malnutrition Universal Screening Tool (MUST)
○ Pain Inventory
○ Breakthrough Pain Assessment Tool (BAT)
○ Rotterdam Elderly Pain Observation Scale (EPOS)
○ Multidimensional Fatigue Index (MFI)
○ Distress Thermometer
○ Edmonton Symptom Assessment Scale (ESAS)
○ Chronic Respiratory Questionnaire (CRQ)
○ Care related Quality of Life for Chronic Heart Failure (CareQoL CHF)
○ Groningen Frailty Indicator (GFI)
○ Geriatric 8 (G8)
○ Hospital Anxiety and Depression Scale (HADS)
○ Cornell Scale for Depression in Dementia (CSDD)
○ Geriatric Depression Scale 15 (GDS15)
○ Delirium Observation Scale (DOS)
○ Delirium-O-Measure (DOM)
○ Pain Assessment in Advanced Dementia (PAINAD)

○ Pain Assessment Scale for Seniors with severe dementia (PACSLAC-D)
○ Brief Fatigue Inventory (BFI)
○ Other, namely:...
○ Experienced Burden by Informal Caregiver (EDIZ)
○ Self-rated Burden Scale (SRB)
○ We do not use measurement tools

50. What is the SPCT physician's position with regard to referred patients?
○ Managing / Treating Physician
○ Co-managing Physician
○ Consulting Physician

V. Coordination & continuity of care

51. What proportion of referrals concerned non-oncology patients?
○ < 20%
○ 20-40%
○ 40-60%
○ 60-80%
○ > 80%

52. Prior to discharge, is the SPCT in touch with the nursing home physician or general practitioner, regarding palliative care at home?
○ Yes, always
○ Only on indication
○ No, that is the responsibility of the managing / treating physician
○ No, because...

53. The following questions concern SPCT continuing advice / counseling after the patient has been discharged. (multiple answers possible)

	Always	Often	Sometimes	Never
Is there follow-up by phone?	○	○	○	○
Is there follow-up in the outpatient clinic?	○	○	○	○
Is there follow-up through community visits, if needed?	○	○	○	○
Follow-up is provided in other ways, namely:...	○	○	○	○

54. Our SPCT's community-based way of working is apparent through: (multiple answers possible)
○ We do not work community-based
○ Composition of the SPCT with professionals from both hospital and community setting
○ Consultation by phone for professionals caring for patients outside the hospital
○ Bedside consultation by SPCT members for patients outside the hospital
○ Community based healthcare professionals perform bedside consultation in hospital
○ Community based healthcare professionals participate in SPCT's multidisciplinary team meeting
○ Otherwise, namely:

55. What activities does the SPCT perform for the purpose of publicity and profiling? (multiple answers possible)
    - ○ Research
    - ○ Education / training (within the hospital)
    - ○ Education / training (outside the hospital)
    - ○ Development of protocols
    - ○ PR / marketing
    - ○ Initiating presentations, conferences, congresses
    - ○ Otherwise, namely:...

VI. SPCT Multidisciplinary team meeting

56. Is there a weekly multidisciplinary team meeting (MTM) of the SPCT?
    - ○ Yes
    - ○ No, our MTM frequency is:.... times per ...
57. What is the average duration of the MTMs? (in minutes)...
58. Which referring disciplines attend the MTMs? (multiple answers possible)

	Standing invitation	When indicated
○ General practitioner	○	○
○ Nursing home physician	○	○
○ Anesthesiology	○	○
○ Internal diseases (oncology)	○	○
○ Gastro-enterology	○	○
○ Geriatrics	○	○
○ Pediatrics	○	○
○ Pulmonary diseases	○	○
○ Neurology	○	○
○ Radiotherapy	○	○
○ Rehabilitation	○	○
○ Nurse practitioner	○	○
○ Oncology nurse	○	○
○ Pain nurse	○	○
○ Community nurse	○	○
○ Hospital nurse	○	○
○ Transfer nurse	○	○
○ Other nurse	○	○
○ Pharmacy	○	○
○ Psychiatry	○	○
○ Psychology	○	○
○ Social worker	○	○
○ Occupational therapy	○	○
○ Physical therapy	○	○

○ Chaplains / spiritual caregiver	○	○
○ Dietician	○	○
○ Secretary	○	○
○ Other discipline, namely...	○	○

59. Does the referring professional attend the MTM? Yes, in principal the referring professional always attends the MTM
    ○ Yes, in principal the referring professional always attends the MTM
    ○ Only when indicated
    ○ No
60. Which patients are discussed in the MTMs?
    ○ All patients
    ○ Only new patients
    ○ Only complex patients
    ○ Only new and complex patients
    ○ Others, namely...
61. How many patients are on average discussed in the MTMs?...
62. Does the referring professional always receive a report of the MTM?
    ○ Yes
    ○ No
63. Does the general practitioner or nursing home physician of the referred patient always receive a report of the MTM?
    ○ Yes
    ○ No
64. Does a member of the SPCT attend MTMs in other departments?
    ○ Yes
    ○ No
65. The SPCT has a standing invitation to attend the MTMs of the following departments: (multiple answers possible)

    ○ Anesthesiology
    ○ Cardiology
    ○ Dermatology
    ○ Ear, Nose, Throat
    ○ Emergency Department
    ○ Endocrinology
    ○ Gastro-intestinal diseases
    ○ Geriatrics
    ○ Gynecology
    ○ Hematology
    ○ ICU
    ○ Internal diseases
    ○ Neonatal care
    ○ Neurology
    ○ Neurosurgery
    ○ Nephrology
    ○ Oncology
    vOphthalmology
    ○ Orthopedic Surgery
    ○ Pediatrics
    ○ Psychiatrics
    ○ Pulmonary diseases
    ○ Rehabilitation
    ○ Rheumatology
    ○ Surgery
    ○ Urology
    ○ Other, namely:...

VII. Quality of care and expertise of the SPCT

66. Are there agreed quality criteria? (multiple answers possible))
    ○ No
    ○ Yes, regarding timing / response to referral
    ○ Yes, regarding level of education of SPCT members
    ○ Yes, regarding method of consultation

○ Yes, regarding advice based on palliative care guidelines
○ Yes, regarding use of measurement instruments / tools
○ Yes, regarding presence at SPCT MTMs
○ Yes, regarding follow-up of given advice
○ Yes, regarding informing patients' general practitioner
○ Yes, regarding collective continuing medical / nursing education
○ Yes, regarding 'care for healthcare professionals'
○ Other criteria, namely:

67. What is the level of education and / or training of the physicians of the SPCT?

	Number of physicians
○ 2- year continuing medical education (CME)	...
○ Cardiff Palliative Medicine Course (postgraduate)	...
○ 8-day medical course	...
○ No additional education and / or training	...
○ Other, namely:	...

68. What is the level of education and / or training of the nurses of the SPCT?

	Number of nurses
○ 1-year continuing nursing education (CNE) Nijmegen	...
○ 1-year continuing nursing education (CNE) Rotterdam	...
○ 1-year continuing nursing education (CNE) Utrecht	...
○ Basic palliative care training	...
○ No additional education and / or training	...
○ Other, namely:	...

69. What is the level of education and / or training of the nurse practitioners of the SPCT?

	Number of nurses
○ Differentiation Palliative Care	...
○ Differentiation Oncology	...
○ Differentiation Pain	...
○ No additional education and / or training	...
○ Other, namely:	...

70. Which members of the SPCT are reimbursed for attending conferences and / or continuing medical / nursing education? (multiple answers possible)

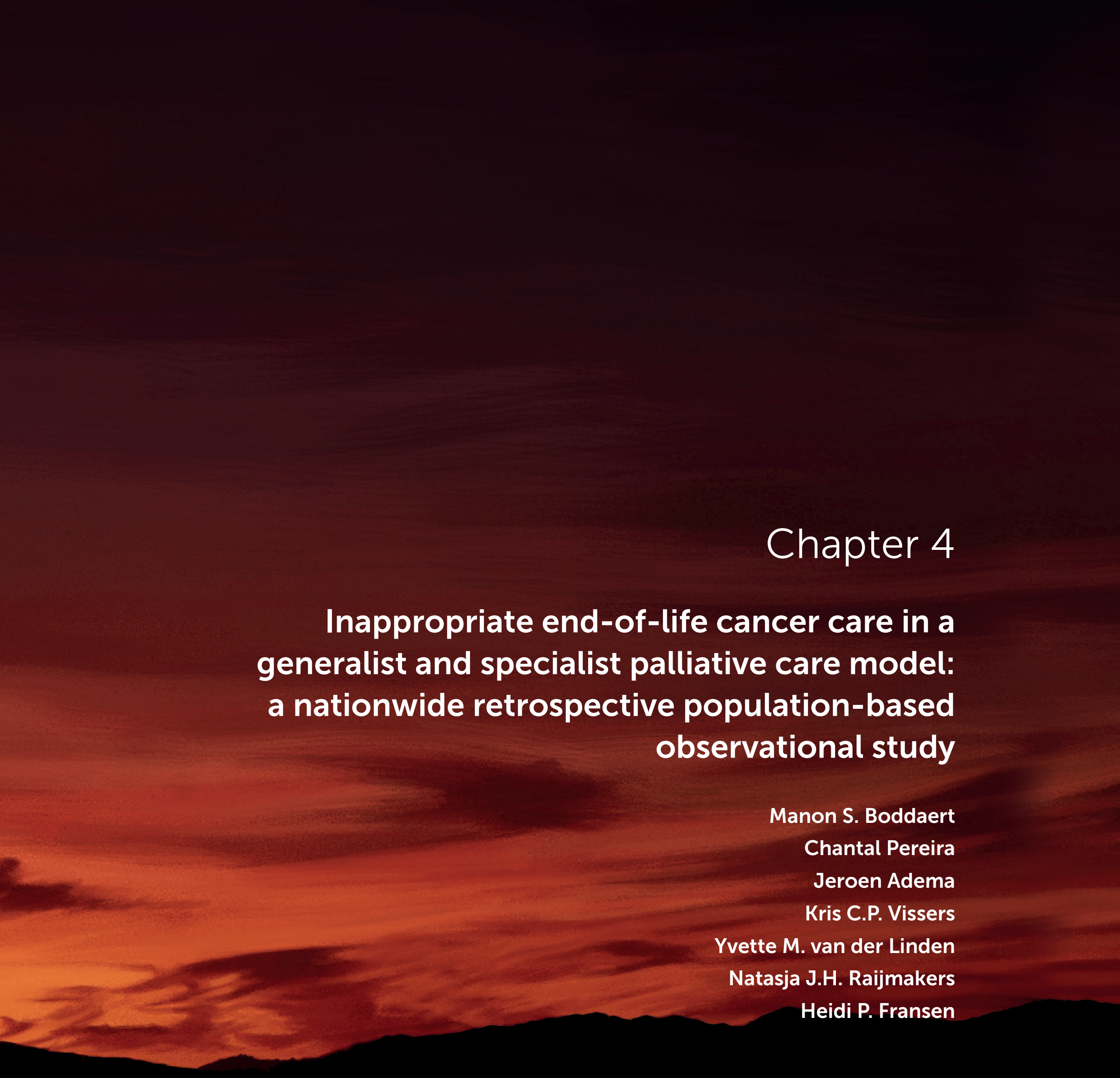
○ General practitioner
○ Nursing home physician
○ Anesthesiology
○ Internal diseases (oncology)
○ Gastro-enterology
○ Geriatrics
○ Pediatrics
○ Pulmonary diseases
○ Radiotherapy
○ Rehabilitation
○ Nurse practitioner
○ Oncology nurse
○ Pain nurse
○ Community nurse
○ Hospital nurse
○ Transfer nurse
○ Pharmacy
○ Psychiatry
○ Psychology
○ Social worker
○ Occupational therapy
○ Physical therapy
○ Chaplains
○ Dietician

○ Neurology ○ Other nurse ○ Secretary

○ Other, namely:... ○ No budget

71. Is there structural attention for selfcare and care for each other in SPCT meetings?
    ○ Yes
    ○ No
72. Is there a burn-out (prevention) programme within the hospital and does the SPCT participate?
    ○ Yes
    ○ Yes, but the SPCT does not participate
    ○ No
73. How would you evaluate the over-all functioning of the SPCT within your hospital?
    0 50 100
    |____|
74. How would you evaluate the quality of consultation provided by the SPCT?
    0 50 100
    |____|
75. What impeding factors are currently influencing the over-all functioning of the SPCT?...
76. What tips and tricks would you suggest to improve over-all functioning of a SPCT?...
77. May the researchers contact you, should results of the survey so require?
    ○ Yes
    ○ No

Thank you for your cooperation!



Chapter 4

Inappropriate end-of-life cancer care in a generalist and specialist palliative care model: a nationwide retrospective population-based observational study

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Abstract

Objective

To evaluate the impact of provision and timing of palliative care (PC) on potentially inappropriate end-of-life care to patients with cancer in a mixed generalist – specialist palliative care model.

Method

A retrospective population-based observational study using a national administrative health insurance database. All 43,067 adults in the Netherlands, who were diagnosed with or treated for cancer during the year preceding their death in 2017 were included. Main exposure was either generalist or specialist PC initiated > 30 days before death (n=16,967). Outcomes were measured over the last 30 days of life, using quality indicators for potentially inappropriate end-of-life care.

Results

In total, 14,504 patients (34%) experienced potentially inappropriate end-of-life care; 2,732 were provided with PC > 30 days before death (exposure group) and 11,772 received no PC or ≤ 30 days before death (non-exposure group) (16% vs. 45%, p < 0.001). Most patients received generalist PC (88%). Patients with PC > 30 days before death were 5 times less likely to experience potentially inappropriate end-of-life care (AOR 0.20; (95% CI: 0.15 to 0.26)) than those with no PC or PC in the last 30 days. Both early (> 90 days) and late (> 30 and ≤ 90 days) PC initiation had lower odds for potentially inappropriate end-of-life care (AOR 0.23 and 0.19 respectively).

Conclusion

Timely access to PC in a mixed generalist - specialist palliative care model was associated with significantly less potentially inappropriate end-of-life care for patients with cancer. Generalist PC may play a substantial role.

Introduction

In high-income countries, over the past decade there has been a growing concern for patients with life-threatening illnesses such as cancer, that life-prolonging medical treatments often prevail over comfort-oriented care near the end of life.[1 2] Thus, medical treatments which are justifiable for patients with a similar diagnosis and good prognosis can turn into unwanted or inappropriate interventions near the end of life, where benefits of treatment no longer outweigh the possible negative effects of continuing treatment.[3] Potentially inappropriate end-of-life care not only has a negative impact on a patient's quality of care at the end of life [4 5], but also raises economic and ethical concerns, since resources are spent on interventions providing little benefit and even possible harm, rather than on care which could be more appropriate for the patient at that stage, such as comfort care or palliative care.[6] Palliative care aims to improve the quality of life of patients with a life-threatening illness or frailty through early identification, careful assessment and treatment of symptoms of a physical, psychosocial and spiritual nature, effective patient-clinician communication, facilitation of complex decision making and advance care planning.[7 8] Over recent years, a growing body of evidence has accumulated supporting that integration of standard oncology care with specialist palliative care is associated with improved quality of life, symptom burden, patient and caregiver satisfaction, healthcare utilisation and possibly survival for patients with advanced cancer.[9-11]

One of the challenges for quality improvement concerning care for patients with a life-threatening condition is to measure quality of care quickly and efficiently with as little burden to patients and their caregivers as possible. To address this concern, Earle et al. previously identified a set of indicators, that can be obtained from administrative data sources, regarding potential overuse of chemotherapy, underuse of hospice services and frequency of emergency room visits, hospitalisations and intensive care unit admissions near the end of life.[12 13] Applying these indicators of potentially inappropriate end-of-life care to administrative data has demonstrated a positive impact of specialist palliative care on potentially aggressive interventions in the last month of life for patients with advanced cancer.[14-16] In the Netherlands however, all healthcare professionals provide generalist palliative care as part of their basic medical skills and competencies. To that end national standards and guidelines are available, although palliative care training is neither integrated nor required in healthcare education yet. There is a community structure of family practitioners and nurses who provide home care, and most primary home care teams and nursing homes provide end-of-life care. If needed, palliative care specialists are asked to provide extra support and share their expertise. As such, a multidisciplinary specialist palliative care team is available in every hospital that provides cancer care. Standards for referral or recommendations for the ratio of specialist - generalist palliative care workforce or for continuity in the delivery of palliative care have not been developed yet.[17 18] The aim of this study is to investigate the association between palliative care and potentially inappropriate end-of-life care for patients with cancer in a healthcare system with a mixed generalist and specialist palliative care model.[18 19]

Methods

Study design

We conducted a retrospective nationwide population-based observational study using administrative data for healthcare utilisation.

Data source

Data were derived from a population-level administrative database held by Vektis[20]. Due to the legal obligation for all people living or working in the Netherlands to have health insurance, this database represents around 99% of approximately 17 million medically insured people in the Netherlands in 2017. Within Vektis, encrypted health card numbers were used to combine patient-level information across several health administrative databases that contain routinely collected full health insurance data from primary, secondary and tertiary care settings.

Study setting and participants

The study was conducted for all decedents who were registered with a Dutch health insurance provider at time of death in 2017. We included all those who were >18 years old and whose record showed specific national Diagnosis-Treatment Combination codes indicating diagnosis or treatment for solid tumours in the year preceding death (Supplement table 1).

Data on provision, timing, continuity and level of palliative care were collected over a period of one year preceding the date of death. Data collection on potentially inappropriate end-of-life care was limited to the last 30 days of life. Overall data collection covered a period between January 1, 2016 and December 31, 2017.

Patient and public involvement

We collected data on an aggregated level with quality indicators that have been accepted as benchmarks to assess the quality of end-of-life care.[21] The patient's perspective was incorporated in the definition of these quality indicators. In our study, as we used the predefined quality indicators, patients were not involved in defining the research question or the outcome measures, nor were they involved in developing plans for design or implementation of the study. No patients were asked to advise on interpretation or writing up of results. The results of this study will be broadly disseminated, i.e., through patient organisations and digital patient communities.

Exposure group

The main exposure was provision of palliative care. This could be either generalist or specialist palliative care. First initiation of palliative care was assessed across all care settings by use of specific national healthcare codes required for reimbursement of palliative care. Healthcare codes were considered to represent initiation of palliative care when they contained the words 'palliative', 'palliative / supportive', 'hospice', when they referred to advance care planning or when a life-expectancy of less than 3 months was an explicit requirement for reimbursement of a specific healthcare code (Supplement table 2). This was done for hospital-, home-, hospice- and nursing home-based care settings and resulted in 200 specified codes and 11 grouped codes. Healthcare codes for disease directed treatments (e.g. palliative chemotherapy or radiotherapy in oncology setting) were considered part of usual care for the majority of patients, where the other dimensions of palliative care (i.e., psychological, social and existential) are not necessarily addressed. Therefore, healthcare codes referring to these treatments were excluded from the palliative care exposure group.

To compose the exposure group, we distinguished between palliative care initiated > 30 days before death, palliative care initiated $\leq$ 30 days before death and no palliative care at all. Patients scoring at least one healthcare code for palliative care initiated > 30 days before death, were assigned to the exposure group.

Non-exposure group

Patients not scoring healthcare codes for palliative care or for whom palliative care was initiated $\leq$ 30 days before death, were assigned to the non-exposure group.

Timing and continuity of palliative care

To evaluate the influence of timing of palliative care on potentially inappropriate end-of-life care we stratified first initiation of palliative care by early, late and very late palliative care. In accordance with previous studies, we defined early palliative care as initiated > 90 days before death[14 15], late palliative care as initiated $\leq$ 90 and > 30 days before death and very late palliative care as initiated $\leq$ 30 days before death. To evaluate continuity of palliative care after initiation we assessed the number of palliative care registrations per patient for each timeframe. We focused on assessing impact of early and late palliative care on potentially inappropriate end-of-life care and excluded very late palliative care from the exposure group. This was done to avoid confounding issues due to overlap with the outcome period (i.e., it would be unclear if palliative care was started prior to or after use of potentially inappropriate care within the last 30 days of life).

Level of palliative care

To assess the proportion of generalist and specialist palliative care, we stratified the specific national healthcare codes required for reimbursement of palliative care by generalist palliative care codes and specialist palliative care codes (Supplement table 2). Generalist palliative care reimbursement can be claimed for palliative care provided by (healthcare organisations employing) healthcare professionals with basic training in palliative care, including but not limited to family physicians, general practitioners, medical specialists (e.g. oncologists, internists, geriatricians, anaesthesiologists, etc.), nurse practitioners and nurses across all care-settings.[17 18] Stratification for generalist palliative care resulted in seven grouped healthcare codes.

Specialist palliative care reimbursement can only be claimed for care provided by individual healthcare professionals with specialty training in palliative care and by healthcare organisations employing a multidisciplinary team of palliative care specialists. For specialist palliative care four grouped healthcare codes were used (Supplement table 2).[17 18]

Patients who were provided with only generalist palliative care were allocated to the generalist palliative care group. Patients provided with at least specialist palliative care were allocated to the specialist palliative care group. Specialist palliative care prevailed over generalist palliative care for the allocation to the groups. Therefore, patients in the specialist palliative care group were provided either with specialist palliative care alone, or with both generalist and specialist palliative care.

Outcomes

We selected population-based quality indicators for end-of-life care based on a body of literature concerning development, validation and benchmarking of these indicators.[12 13 22 23] Six population-based quality indicators measuring potentially inappropriate or aggressive end-of-life care were used to evaluate quality of care in the last 30 days of life: provision of chemotherapy, frequency of emergency room visits ($\geq$ 2) and hospital admissions ($\geq$ 2), length of hospitalisations (> 14 days), intensive care unit admissions ($\geq$ 1) and hospital death. Patients scoring any one of these items were defined as receiving potentially inappropriate end-of-life care. [12 14 24] As each patient could score multiple indicators, we calculated the mean composite score by adding up the numbers of patients scored per quality indicator and dividing this sum by the number of patients receiving potentially inappropriate end-of-life care.[24] This reflects the mean number of indicators per patient.

Statistical analysis

Descriptive statistics were used to assess provision, timing and continuity of palliative care by itself and in relation to receiving potentially inappropriate end-of-life care. Summary statistics are presented, differences were tested using chi-square test. Multivariable logistic regression was used and adjusted odds ratios (AORs) and corresponding 95% CIs were computed to assess the impact of palliative care as well as the impact of early and late palliative care on the likelihood of receiving potentially inappropriate end-of-life care.

In the model we adjusted for age, sex and cancer diagnosis (type and number of (i.e., multiple) diagnoses). A 2-tailed P value less than .05 was considered statistically significant. All analyses were conducted in R (version 3.4.4).[25]

Results

Overall, 43,067 adults were diagnosed with or treated for cancer in the year preceding their death in 2017 and palliative care was initiated for 32,768 (76%). For 16,967 patients (39%) palliative care was provided > 30 days before death (exposure group). This was initiated early for 8,882 patients (20%) and late for 8,085 patients (19%). For 15,801 patients (37%) palliative care was provided ≤ 30 days before death and 10,299 patients (24%) did not receive palliative care at all (non-exposure group). Characteristics regarding age, sex and cancer diagnosis were similar for both groups (table 1).

Table 1. Cohort characteristics

Characteristic	**Exposure group[a]**		**Non-exposure group[b]**		**Overall**	
Age						
Mean (range)	*72 (19 – 101)*		*74 (19–104)*		*73 (19 – 104)*	
	N	%	N	%	N	%
Overall no. of decedents	16,967	39	26,100	61	43,067	100
Sex						
Male	9,110	54	15,452	59	24,562	57
Female	7,857	46	10,648	41	18,505	43
Most prevalent cancer types						
Genito-urinary tract cancer	3,851	23	6,432	25	10,283	24
Lung cancer	3,525	21	6,169	24	9,694	23
Colorectal cancer	2,601	15	3,277	13	5,878	14
Breast cancer	1,537	9	2,317	9	3,854	9

[a]Palliative care initiated > 30 days before death. [b]Palliative care initiated ≤ 30 days before death or not at all.

During the last 30 days of life, 14,504 patients (34%) experienced potentially inappropriate end-of-life care; 2,732 patients in the exposure group and 11,772 patients in the non-exposure group (16% vs. 45%, p < 0.001). All quality indicators rated lower for patients in the exposure group; ≥ 2 ER-visits (6% vs 16%, p<0.001), ≥ 2 hospital admissions (4% vs 12%, p<0.001), > 14 hospital days (3% vs 11%, p<0.001), chemotherapy (3% vs 6%, p<0.001), ICU-admission (1% vs 9%, p<0.001) and hospital death (8% vs. 28%, p<0.001). However, the average number of indicators scored per patient, i.e., the mean composite score, was similar (1.6 vs 1.8) for both groups (table 2).

Table 2. Indicators of potentially inappropriate end-of-life care[a].

Characteristic	Exposure group		Non-exposure group		Total population		
	N	%	N	%	N	%	p-value
Overall no. of decedents	16,967	39	26,100	61	43,067	100	
Inappropriate EoL[b] care[c]							
Yes	2,732	16	11,772	45	14,504	34	<0.001
No	14,235	84	14,328	55	28,563	66	
Indicators							
≥ 2 emergency room visits	1,024	6	4,069	16	5,093	12	<0.001
≥ 2 hospital admissions	755	4	3,040	12	3,795	9	<0.001
> 14 days of hospitalisation	451	3	2,852	11	3,303	8	<0.001
Chemotherapy	526	3	1,556	6	2,082	5	<0.001
ICU admission	200	1	2,246	9	2,446	6	<0.001
Hospital death	1,382	8	7,194	28	8,576	20	<0.001
Mean composite score[d]	1.6		1.8		1.7		
Initiation of palliative care (mean)[e]	4.5		0.7		2.7		

[a] in the last 30 days before death. [b]EoL; end of life. [c]qualification is rendered positive when 1 out of 6 indicators is scored. [d]total amount of 6 indicators divided by number of patients receiving potentially inappropriate end-of-life care. [e]in months before death.

Timing and continuity of palliative care

On average, early palliative care was started 6.8 months before death and late palliative care 2.1 months before death. We found a small but statistically significant difference in potentially inappropriate end-of-life care between early and late start of palliative care in favour of the latter (18% vs. 14%, p < 0.001). More specifically in the indicators for emergency room visits, hospital days, ICU-admission and hospital death (table 3). The median number of palliative care registrations for patients provided with early palliative care was 3 (IQR 1-6) from initiation to 3 months before death, 4 (IQR 2-9) between 3 - 1 months and 7 (IQR 4-11) in the last 30 days. For patients provided with late palliative care the median number of palliative care registrations was 2 (IQR 1-5) between 3-1 months before death and 8 (IQR 5-12) in the last 30 days (table 3).

Table 3. Indicators of potentially inappropriate end-of-life care[a] stratified by timing of palliative care.

Characteristic	**Early PC[b]**		**Late PC[c]**		**Exposure group**		
	N	%	N	%	N	%	p-value
Overall no. of decedents	8,882	52	8,085	48	16,967	100	
Inappropriate EoL care[d,e]							
Yes	1,568	18	1,164	14	2,732	16	**<0.001**
No	7,314	82	6,921	86	14,235	84	
Indicators							
≥ 2 emergency room visits	583	7	441	6	1,024	6	**<0.05**
≥ 2 hospital admissions	397	5	358	4	755	4	0.895
> 14 days of hospitalisation	258	3	193	2	451	3	**<0.05**
Chemotherapy	268	3	258	3	526	3	0.514
ICU admission	132	2	68	1	200	1	**<0.001**
Hospital death	825	9	557	7	1,382	8	**<0.001**
Mean composite score[f]	1.6		1.6		1.6		
Initiation of palliative care (mean)[g]	6.8		2.1		4.5		
Number of PC registrations >3 mo[h]	3 (1 - 6)		-		3 (1 - 6)		
Number of PC registrations 3-1 mo[h]	4 (2 - 9)		2 (1 - 5)		3 (1 - 7)		
Number of PC registrations < 1 mo[h]	7 (4 - 11)		8 (5 - 12)		8 (4 - 11)		

[a] in the last 30 days before death. [b] early palliative care; initiated > 90 days before death. [c] late palliative care; initiated ≤ 90 days and > 30 days before death. [d] EoL; end of life. [e] qualification is rendered positive when 1 out of 6 indicators is scored. [f] total amount of 6 indicators divided by no. patients receiving potentially inappropriate EoL care. [g] in months before death. [h] median and interquartile range.

Level of palliative care

We found the proportion of specialist palliative care in relation to generalist palliative care to be 12%, regardless of whether palliative care was provided early, late or very late (table 4). In the exposure group (n = 16,967) specialist palliative care (n = 2,024) consisted of specialist palliative care alone in 1% of patients (n = 141) and of both generalist and specialist palliative care in 11% (n = 1,883). The majority of patients (88%) was provided with generalist palliative care alone.

Table 4. Level of palliative care stratified by timing of palliative care (n = 32 768)

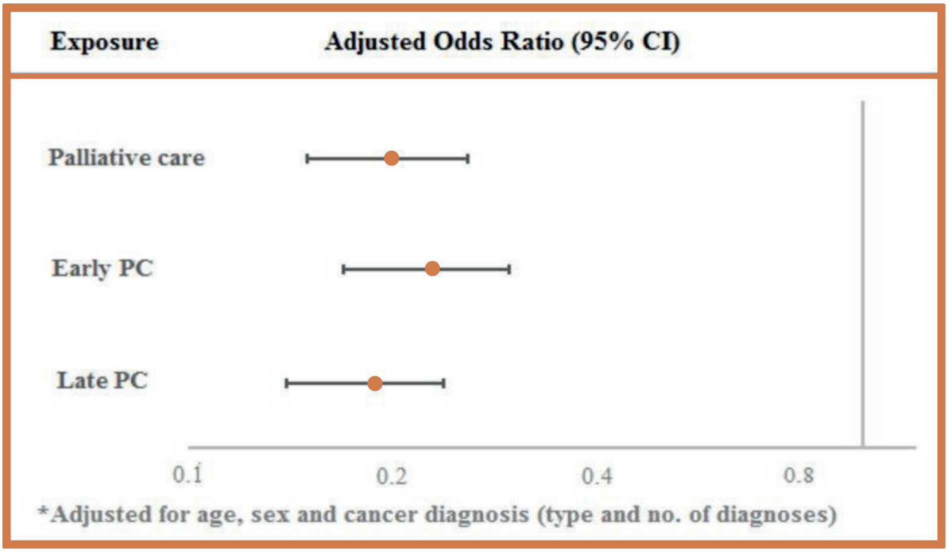
Characteristic	Early PC[a]		Late PC[b]		Very late PC[c]	
	N	%	N	%	N	%
Overall no. of decedents	8,882	27	8,085	25	15,801	48
Proportion of specialist palliative care	1,027	12	997	12	1,909	12
Proportion of generalist palliative care	7,855	88	7,088	88	13,892	88

[a]early palliative care; initiated > 90 days before death. [b]late palliative care; initiated ≤ 90 days and > 30 days before death. [c] very late palliative care; initiated ≤ 30 days before death.

Impact of provision and timing of palliative care on the likelihood of receiving potentially inappropriate end-of-life care.

Adjusted for age, sex and type and n° of cancer diagnoses, patients receiving palliative care more than 30 days before their death (exposure group) were five times less likely to experience potentially inappropriate end-of-life care (adjusted OR 0.20; 95% CI 0.15 to 0.26) than patients who received palliative care less than 30 days before their death or not at all (non-exposure group). Sub analysis of the exposure group showed lower odds for potentially inappropriate end-of-life care with late initiation of palliative care (≤ 90 and > 30 days before death; adjusted OR 0.19; 95% CI 0.14 to 0.24) than with early initiation of palliative care(> 90 days before death; adjusted OR 0.23; 95% CI 0.17 to 0.30) (figure 1).

Fig. 1. Association between palliative care (PC) and potentially inappropriate end-of-life care.*



*Adjusted for age, sex and cancer diagnosis (type and no. of diagnoses)

Discussion

Among 43,067 patients with cancer who died in the Netherlands in 2017 we found that more than one third of patients experienced potentially inappropriate care in the last month of their life. Patients who received palliative care prior to the last month of their lives were five times less likely to experience potentially inappropriate care in the last month of their life than patients provided with palliative care in the last month of life or not at all. Both early and late palliative care exposure were similarly associated with lower odds for potentially inappropriate care. For most patients, palliative care consisted of generalist palliative care, regardless whether it was provided early, late or very late.

Strengths and limitations

To our knowledge, this is the first nationwide population-based observational study evaluating the impact of a mixed generalist and specialist palliative care model on quality of end-of-life care for patients with cancer, provided across all care settings. Another strength of this study lies in the use of a population-level administrative database covering nearly all Dutch residents. This minimizes selection bias and renders our findings generalizable for comparison to other populations of patients with cancer. However, several limitations need mentioning. Firstly, population-based quality indicators are used on an aggregated level and cannot be used as indicators of inappropriate care for individual patients; clinical factors may justify an acute care intervention and personal preferences may differ. Hence, our strict use of the term ‘potentially inappropriate end-of-life care’ throughout the article. Secondly, as administrative data are not primarily captured for the purpose of quality assessment, a general limitation results from a lack of clinical information about the content of care provided. Thirdly, our findings are based on a retrospective study design. Therefore, we could not determine whether healthcare professionals were aware of their patients being in their last months of life nor whether care took place in that context.

Comparisons with other studies

When we compare our results to previous national and international studies in high-income countries with a similar healthcare system, it shows a higher percentage of potentially inappropriate end-of-life care for patients with cancer in the Netherlands compared to Canada (34% vs 22.4%)[24] and a consistently low percentage of hospital death (19% vs 29%) as well as a low percentage of chemotherapy use (5% vs 17%) in the Netherlands compared to Belgium.[26 27] In contrast we find only 12% of patients received specialist palliative care vs 47% in Belgium and 25.8% in Canada.[19 27] In 2017 reimbursement for specialist palliative care in Dutch hospitals was difficult to obtain as a result of complicated administrative financial regulations. Therefore the actual proportion of specialist palliative care provided is likely to be larger than our data suggest. However, a previous study showed a limited number of referrals to specialist palliative care teams in Dutch hospitals in 2014 (median 77 consultations per year, range 2-680).[28] In relation to other countries actual underutilisation of specialist palliative care services, complex registration of specialist palliative care provided, and a lack of standards for referral or the ratio of specialist - generalist palliative care workforce may contribute to the low proportion of patients receiving specialist palliative care in the Netherlands. This is currently subject of further research.

Considering that most palliative care provided in this study was generalist palliative care, this comparison of studies seems to suggest that generalist palliative care improves end-of-life care through preventing hospital death and use of chemotherapy in the last month before death. Improving access to specialist palliative care for patients with complex palliative care needs may assist in lowering the overall percentage of patients experiencing potentially inappropriate end-of-life care.

A recent systematic review of population-based quality indicators found only one previous study that established a benchmark for healthcare systems not providing overly aggressive end-of-life care.[13 29] In this preferred healthcare system less than 10% of patients receive chemotherapy in the last 14 days of life, less than 4% have multiple hospitalisations or emergency room visits or are admitted to the ICU in the last month of life and less than 17% die in an acute care institution. Applying this benchmark to our results for the patients receiving palliative care very late or not at all, leaves room for improvement for nearly all quality indicators. However, for patients who were provided with palliative care prior to their last month of life, nearly all benchmark requirements were met. These results strongly suggest a need to focus local and national policy on increasing the number of people with cancer receiving palliative care early in their disease trajectory.

Contrary to what other studies have shown[14 15 30], in this study early initiation of palliative care has a weaker association with less potentially inappropriate end-of-life care than late initiation of palliative care. In their studies, while using similar definitions for early and late palliative care, both Hui et al. and Scibetta et al. did not exclude palliative care provided during the outcome period (i.e., last 30 days before death) from their late palliative care group. This may have reflected on the outcomes for potentially inappropriate end-of-life care in this group, thereby confounding comparison with our results. As Qureshi et al. used different timeframes for the early and late exposure group in their large population-based study, we could not compare our results.

Comparing the median number of palliative care registrations between early and late provision of palliative care as presented in table 3 sheds some light on our ambivalent results. Patients provided with early palliative care have more palliative care registrations between 3 and 1 month before death than patients provided with late palliative care. This might indicate that these patients have more complex palliative care needs that potentially require more healthcare utilisation at the end of life. In both early and late palliative care groups care consisted of generalist palliative care with a similarly limited proportion of specialist palliative care (12%). Comparing specialist and generalist palliative care visits around critical timepoints, specialist palliative care visits emphasised coping and prognostic awareness, whereas oncologic care focused on cancer treatment and management of medical complications.[31] Early referral of patients with complex palliative care needs to specialist palliative care may well improve quality of care for these patients.[32]

Recent literature shows that patients with life-threatening illness or frailty continue to receive non-beneficial treatments at the end of life, leading to poor quality, high cost care in high-income countries.[33 34] Despite ample evidence that specialist palliative care improves quality of life, symptom burden and quality of end-of-life care for these patients and their families,[10 11 16 35] and professional organisations recommend earlier and routine co-management by palliative care specialists,[1 36 37] there appears to be little improvement over the past two decades.[2 24 34] With the foreseen increase in patients with palliative care needs[38 39], comes a workforce shortage in palliative care specialists and a need for all healthcare professionals to deliver generalist palliative care.[17 40 41] Our data confirm that generalist palliative care can play a substantial role.[41 42] Moreover, as we established as yet a limited involvement of specialist palliative care services, standards or recommendations on use of internationally expert-based referral criteria may help optimize quality of end-of-life care through timely access to specialist palliative care for patients with complex palliative care needs.[11 43]

Conclusion and policy implications

This study shows that initiation of palliative care prior to the last month of life is associated with significantly less potentially inappropriate end-of-life care for patients with cancer. As generalist palliative care may play a substantial role, these results imply a need to focus local and national policy on improving access to generalist and specialist palliative care for every patient.

Sustained investment in training of all healthcare professionals can improve timely identification of palliative care needs in the individual patient, distress caused by the disease and its impact on the person as a whole. This will lead to a larger number of patients receiving generalist palliative care earlier in their disease trajectory. Also, improving early access to specialist palliative care for patients with complex palliative care needs will lead to more prognostic awareness and better quality of end-of-life care for these patients. Recommendations on use of standardised referral criteria for specialist palliative care and funding of integrated palliative care models are needed to support these improvements. As such, these improvements to end-of-life care may have major implications for health policy. Further prospective research is needed to substantiate the findings of this retrospective study.

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Competing interest

None declared.

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Supplement

Supplement Table1. Vektis database - Oncology identification codes

Oncology identification	Specialist code	Diagnostic code	Oncology identification	Specialist code	Diagnostic code	Oncology identification	Specialist code	Diagnostic code
Cancer of breast	0303	0318	**Cancer of breast, secondary**	0304	0221	**Cancer of other respiratory & intrathoracic**	0322	1305
	0313	0811		0304	0222		0322	1306
	0361	0105		0304	0223		0322	1307
				0304	0224		0303	0314
				0304	0225		0313	0623
				0304	0226		0313	0624
				0304	0230		0313	0629
Cancer of bronchus, lung	0303	0313	**Cancer, other & unspecified primary**	0316	6119	**Cancer of Head & Neck**	0303	0358
	0313	0621		0303	0352		0301	0358
	0313	0622		0303	0363		0302	0019
	0322	1303		0305	1150		0302	0020
	0322	1304		0305	1199		0302	0021
	0328	1210		0316	6115		0302	0040
	0328	1220		0316	6120		0302	0041
	0328	1230		0307	OM17		0302	0042
	0328	1240		0361	0111		0302	0060
	0328	1250		0313	0899		0302	0061
	0328	1270		0303	0359		0302	0062
	0328	1310		0318	0906		0302	0063
	0328	1340		0335	0211		0302	0064
	0328	1430		0361	0109		0302	0065
	0328	1440		0389	0100		0302	0066
	0328	1460		0308	1145		0302	0067
	0328	1470		0308	1150		0302	0068
	0328	1510		0313	0243		0302	0069
	0328	1530		0313	0263		0302	0072
	0328	1595		0313	0264		0302	0084
	0328	1420		0303	0301		0303	0306
	0361	0103					0303	0354
							0313	0801
							0361	0101
Cancer of liver & bile duct	0303	0367	**Cancer of colon**	0303	0333	**Cancer of other GI organs, peritoneum**	0303	0357
	0313	0955		0303	0347		0303	0331
	0316	6118		0313	0927		0318	0810
	0318	0712		0318	0607		0361	0102
	0318	0735		0318	0610		0303	0349
	0303	0348					0313	0979
Cancer of stomach	0303	0346	**Cancer of esophagus**	0303	0319	**Cancer of pancreas**	0303	0332
	0313	0914		0313	0904		0313	0964
	0318	0407		0318	0307		0318	0755

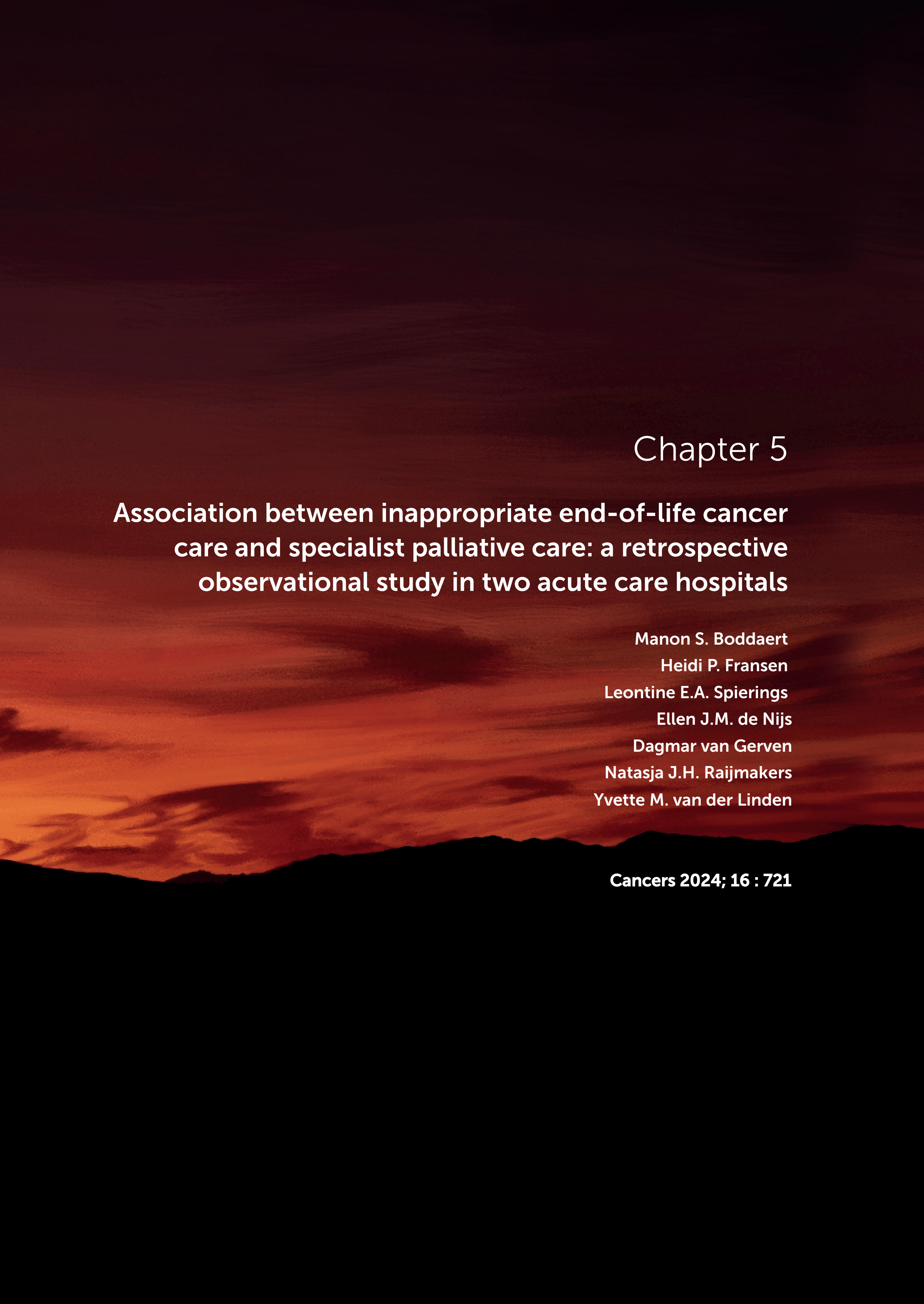
Supplement Table1. Vektis database - Oncology identification codes (continued)

Oncology identification	Specialist code	Diagnostic code	Oncology identification	Specialist code	Diagnostic code	Oncology identification	Specialist code	Diagnostic code
Cancer of rectum & anus	0303 0303	0334 0335	**Cancer of thyreoid**	0303 0313 0313	0303 0214 0291	**Melanoma**	0302 0303 0313	0001 0350 0842
Cancer of female genital organs	0307 0313 0307 0307 0307 0307 0307 0307 0313 0313 0361	0M13 0822 0M14 0M15 0M16 0M99 0M11 0M12 0821 0823 0106	**Cancer of brain & nervous system**	0330 0304 0308 0308 0308 0308 0308 0308 0308 0308 0308 0308 0308 0308 0308 0308 0308 0308 0308 0308 0313	9921 0353 1101 1105 1110 1115 1120 1125 1130 1135 1140 1810 2101 2105 2110 2115 2120 2125 2130 3101 0802	**Cancer of brain & nervous system (cont'd)**	0316 0316 0327 0330 0330 0330 0330 0330 0330 0330 0330 0330 0330 0330 0330 0330 0330 0330 0330 0330 0361	3505 6113 0316 0201 0202 0204 0211 0212 0213 0221 0222 0223 0231 0232 0233 0241 0242 0243 0251 0299 0108
Cancer of male genital organs & prostate	0306 0306 0306 0306 0313 0306 0306 0306 0313 0361	0050 0060 0069 0092 0831 0040 0045 0048 0832 0107						
Cancer of bone & connective tissue	0305 0313 0313 0316 0361	1140 0841 0843 6107 0104	**Cancer of kidney & renal pelvis**	0306 0303 0306 0306 0313 0316	0025 0370 0010 0016 0834 6116	**Cancer of other urinary organs**	0306 0306 0306 0313 0313	0020 0070 0078 0833 0839
Cancer of bladder	0306 0306	0030 0084	**Secondary malignancies**	0303 0305 0322 0330	0360 1110 1308 0203	**Other oncological diseases**	8418	0513
Pain, due to malignancy	0324	0715						

Supplement Table 2. Characteristics of healthcare codes for generalist and specialist palliative care across care-settings

Reimbursement code	Type of care	Billable for	Billable timeframe	Location of care
Weighing treatment options in light of advance care planning	Generalist palliative care	MO[a] / NP[b]	Throughout disease trajectory	Hospital
Supportive care/ palliative care in oncology setting	Generalist palliative care	MO[a] / NP[b]	Throughout disease trajectory	Hospital
Interdisciplinary palliative care team	Specialist palliative care	Multi-disciplinary	Throughout disease trajectory	Hospital
*Intensive home / hospice care**	Generalist palliative care	Family physician	Prognosis < 3 months	Home / Hospice
Multidisciplinary meeting with primary and specialty palliative care providers	Specialist palliative care	Family physician	Throughout disease trajectory	Home / Hospice
Bed-side palliative care consultation	Specialist palliative care	Family physician	Prognosis < 3 months	Home / Hospice
Hospice care at home	Generalist palliative care	Nurse	Prognosis < 3 months	Home
Community hospice care	Generalist palliative care	Nurse	Prognosis < 3 months	Hospice
*Intensive long term care**	Generalist palliative care	Physician / Nurse	Prognosis < 3 months	Nursing home
*Intensive long term care at home**	Generalist palliative care	Physician / Nurse	Prognosis < 3 months	Home
Palliative care unit	Generalist palliative care	Multi-disciplinary	Prognosis < 3 months	Nursing home

[a] MO; medical oncologist. [b] NP; nurse practitioner. * This reimbursement code refers to intensification of care for chronically or seriously ill patients in the last phase of their life.



Chapter 5

Association between inappropriate end-of-life cancer care and specialist palliative care: a retrospective observational study in two acute care hospitals

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Cancers 2024; 16 : 721

Abstract

Background

A substantial number of patients with life-threatening illnesses like cancer receive inappropriate end-of-life care. Improving their quality of end-of-life care is a priority both for patients and their families as for public health.

To investigate the association between provision, timing and initial setting of hospital-based specialist palliative care and potentially inappropriate end-of-life care for patients with cancer in two acute care hospitals in the Netherlands we conducted a retrospective observational study using hospital administrative databases.

Methods

All adults diagnosed with or treated for cancer in the year preceding their death in 2018 or 2019 were included. Main exposure was hospital-based specialist palliative care initiated >30 days before death. Outcome measures in the last 30 days of life were six quality indicators for inappropriate end-of-life care (i.e.,, ≥2 ED-visits, ≥2 hospital admissions, >14 days hospitalisation, ICU-admission, chemotherapy, hospital death). Using multivariable logistic regression, adjusted odds ratios (AORs) and corresponding 95% CIs were computed for the association between specialist palliative care provision, timing and initial setting, and potentially inappropriate end-of-life care.

Results

We identified 2,603 deceased patients, of whom 13% (n=359) received specialist palliative care >30 days before death (exposure group). Overall, 27% (n=690) received potentially inappropriate end-of-life care: 19% in the exposure group versus 28% in the non-exposure group (p< 0.001). The exposure group was nearly two times less likely to receive potentially inappropriate end-of-life care (AOR 0.55; 95% CI 0.42 to 0.74). Early (>90 days) and late (≤90 and >30 days) initiation of specialist palliative care as well as outpatient and inpatient initiation were all associated with less potentially inappropriate end-of-life care (AOR 0.49; 0.62; 0.32 and 0.65, respectively).

Conclusion

Timely access to hospital-based specialist palliative care is associated with less potentially inappropriate end-of-life care for patients with cancer. Outpatient initiation of specialist palliative care seems to enhance this result.

Introduction

Over recent decades, concern has grown that when patients with life-threatening illnesses such as advanced cancer near the end of their life, life-prolonging medical treatments often prevail over comfort-oriented care.[1 2] Disease-directed treatments or interventions that are appropriate for patients with a similar diagnosis in good clinical condition may then evolve into inappropriate interventions, as possible negative effects outweigh the expected benefits.[3] Aside from reducing quality of care and ultimately the patient's quality of life ,[4 5] this potentially inappropriate end-of-life care also raises economic and ethical concerns, as healthcare resources are spent on interventions providing little benefit and even potential harm, rather than on care that would be more appropriate for a patient at that stage.[6]

Palliative care aims to improve the quality of life of patients with a life-threatening illness or frailty through early identification, careful assessment and treatment of symptoms of a physical, psychosocial and spiritual nature, effective patient-clinician communication, facilitation of complex decision-making and advance care planning.[7 8] A growing body of evidence has demonstrated that integration of specialist palliative care (SPC) into oncology care leads to improved quality of life, lower symptom burden, higher patient and caregiver satisfaction, less healthcare utilisation and possibly longer survival for patients with advanced cancer.[9-11] This is found especially when SPC is provided early and regularly[9-11] and when it is initiated in outpatient setting rather than in inpatient setting.[12-14]

In the Netherlands, palliative care is mostly provided by healthcare professionals without formal palliative care training, so-called generalists in palliative care.[15-17] To support them, professional standards and guidelines for palliative care are available and every Dutch hospital providing cancer care is required to have a multidisciplinary SPC team available to provide additional support and expertise.[18] Previous research showed that on average less than 1 percent of the total annual number of admitted patients was referred to SPC teams in Dutch hospitals, whereas a referral rate of 3-4% would seem more appropriate based on SPC utilisation data from UK, Australia and USA.[19-23] A recent population-based observational study showed a higher percentage of potentially inappropriate end-of-life care for patients with cancer in the Netherlands compared to Canada (34% vs 22%).[24 25] Only 9% of all deceased patients with cancer in the Dutch study received SPC in the year preceding their death compared to 29% in Canada and 47% in Belgium.[26 27] As it is known from controlled studies that patients with cancer or other life-limiting diseases who are provided with SPC have lower healthcare utilisation at the end of life,[9 28-30] potential under-utilisation of SPC services may contribute to this high proportion of patients receiving potentially inappropriate end-of-life care in the Netherlands. Gaining a better understanding of SPC provision and its benefits may increase awareness for referral and contribute to improving quality end-of-life care.

The aim of this study was to assess the association between hospital-based SPC provision, timing and initial setting, and potentially inappropriate end-of-life care in cancer patients in two acute care hospitals in the Netherlands. We hypothesised that the provision of hospital-based SPC is associated with less potentially inappropriate end-of-life care and that early provision and initiation in the outpatient setting may have an enhancing effect.

Methods

Study design

We conducted a multicentre retrospective observational study using hospital administrative data to evaluate healthcare utilisation at the end of life and specialist palliative care provision in the year prior to death in 2018 or 2019.

Study setting and participants

The study was conducted in two acute care hospitals in the Netherlands; one university medical centre and one general hospital. Both hospitals have between 20.000-25.000 admissions per year and in 2017 had an annual referral rate to their SPC team of 1.5%, which were both in the top 25% of SPC referral rates of Dutch hospitals.[19]

All adult deceased patients who were registered in these hospitals at the time of their death in 2018 or 2019 were included, providing their electronic medical record showed an ICD-10 code indicating diagnosis or treatment for solid malignancies (i.e.,, ICD-10 codes C00 – C43 and C45- C76) or metastases (C77-C80) in the year preceding death.[31] The latter group includes both unknown primary cancers and so-called malignancies of other secondary and unspecified sites. As treatment strategies and disease trajectories for patients with haematological malignancies tend to differ from patients with solid malignancies, these patients were excluded. In addition, patients with basal cell carcinoma of the skin were excluded as this diagnosis normally does not progress to advanced cancer and these patients probably died through other non-cancer causes.

Data source and extraction

Data were derived from HiX® (healthcare information exchange) electronic medical records stored in a single clinical data repository in each hospital. Data intelligence units in both participating hospitals built a research specific query for data extraction. The query was built to extract data on provision, timing and intensity, and initial setting of SPC over a period of one year preceding the date of death. Data collection on potentially inappropriate end-of-life care was restricted to the last 30 days of life. Collected data from both hospitals were deidentified before analysis.

Specialist palliative care provision

Provision of SPC was assessed by use of 1) specific national Diagnosis-Treatment Combination (DTC) codes required for reimbursement of SPC in a hospital setting; 2) specific appointment codes administratively attached to each consultation provided by the SPC team (Supplement).

DTC codes for disease directed treatments with palliative intent (e.g., palliative chemotherapy or palliative radiotherapy) were considered part of usual care by medical oncologists and radiation oncologists and were therefore not defined as specialist palliative care provision.

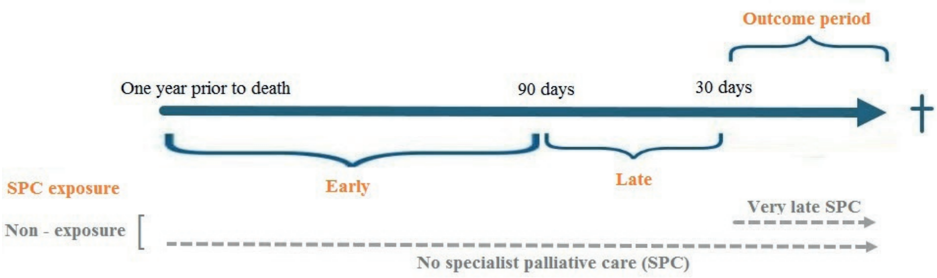
Exposure group

To compose the exposure group, we distinguished between specialist palliative care initiated > 30 days before death, specialist palliative care initiated ≤ 30 days before death and no palliative care at all. Patients for whom SPC was initiated >30 days before death, were assigned to the exposure group.

Non exposure group

Patients were allocated to the non-exposure group when they had no registrations for SPC in the year before death, or when SPC was initiated ≤ 30 days before death (very late SPC) (Figure 1). This was done to ensure the exposure (receiving SPC) was initiated before measuring the outcome (potentially inappropriate care in the last 30 days of life).

Figure 1. Specialist palliative care exposure and non-exposure group



Timing of SPC

To assess the influence of timing on potentially inappropriate end-of-life care we performed a subgroup analysis of early and late initiation of SPC in the exposure group compared to the non-exposure group. In accordance with previous studies, we defined early palliative care as initiated > 90 days before death,[12 13] and late palliative care as initiated ≤ 90 and > 30 days before death. As mentioned, very late palliative care was separately defined as initiated ≤ 30 days before death and assigned to the non-exposure group (Figure 1).

To report the intensity of SPC provision in the exposure group we also assessed the median number of SPC consultations per patient for each timeframe (i.e.,, number of SPC consultations > 90 days, ≤ 90 and > 30 days, and ≤ 30 days before death).

Initial setting of SPC

To assess association between initial setting of SPC provision and potentially inappropriate end-of-life care, we conducted a subgroup analysis for inpatient and outpatient initiation of SPC in the exposure group compared to the non-exposure group. Subgroups were composed based on inpatient and outpatient appointment codes that were administratively linked to the initial consultation provided by the SPC team (Supplement table 1).

Outcome measures

To assess quality of care in the last 30 days of life we selected population-based quality indicators for end-of-life care based on literature regarding the development, validation and benchmarking of these indicators.[32-35] Six population-based quality indicators measuring potentially inappropriate or aggressive end-of-life care were used: provision of chemotherapy, frequency of emergency room visits (≥ 2) and hospital admissions (≥ 2), length of hospitalisation (> 14 days), intensive care unit admissions (≥ 1) and hospital death. Patients scoring one or more of these items were defined as receiving potentially inappropriate end-of-life care. [12 24 33] For these patients, the mean composite score was calculated, representing the mean number of indicators per patient.[24]

In preparation for analysis, databases from both hospitals were merged and adapted: 1) data from patients that had been registered in both hospitals were combined to avoid duplicates, 2) admission and discharge on the same day was considered as day care and therefore not counted as an admission, 3) for patients with missing admission data but a registered death in the hospital, the number of admissions was set at one, 4) registered admissions that started > 30 days before death and continued within the timeframe of the last 30 days were counted as admission. The subsequent number of hospitalisation days was calculated from day 30 before death to date of discharge.

Statistical analysis

Descriptive statistics were used to assess provision, timing and intensity, and initial setting of SPC and potentially inappropriate end-of-life care. Differences were tested using chi-square test (categorical variables) and t-test (continuous variables). Multivariable logistic regression was used to assess the association between SPC provision, timing and initial setting and receiving potentially inappropriate end-of-life care. Adjusted odds ratios (AORs) and corresponding 95% CIs are reported. To enable comparison to other studies and to control for case-mix variations in our model, we adjusted for age, sex and cancer diagnosis. A 2-tailed P value less than .05 was considered statistically significant. All analyses were conducted in SPSS (version 25.0.0.2.).

Results

In total, 2,603 patients diagnosed with or treated for cancer in the year preceding their death in 2018 or 2019 were included. The mean age was 72 years (range 18-97) and most patients were male (56%). The three most prevalent cancer diagnoses were non-colorectal gastro-intestinal cancers (19%), lung cancer (14%), and cancers of the genito-urinary tract (12%) (Table 1).

Specialist Palliative Care provision

In total, 792 patients (30%) received SPC in the last year of life. In 359 patients (14%) SPC was provided > 30 days before death (exposure group), of which 6% was initiated early (> 90 days before death) and 8% late (≤ 90 and > 30 days before death). The remaining 433 patients (17%) were provided with very late SPC (≤ 30 days before death) and duly assigned to the non-exposure group (Table 1).

In the exposure group deceased patients were younger and more often female. Gynaecologic cancer was more prevalent in the exposure group, 8% vs 5% (p = 0.035), whereas genito-urinary tract cancer and breast cancer were more prevalent in the non-exposure group, 8% vs 13% (p=0.02) and 3% vs 6% (p= 0.024) respectively (Table 1).

Table 1. Sociodemographic and clinical cohort characteristics.

Characteristic	**Total**		**Exposure group**[a]		**Non-exposure group**[b]		**P-value**
	N	%	N	%	N	%	
Overall no. of decedents	2,603	100	359	14	2,244	86	
Age							
Mean (range)	72 (18 – 97)		67 (21 – 95)		73 (18 – 97)		**<.001**
Sex							**<.001**
Male	1,461	56	169	47	1,292	58	
Female	1,142	44	190	53	952	42	
Prevalence cancer diagnoses*							
*Non-colorectal GI cancers***	492	19	78	22	414	18	.141
Lung cancer	359	14	55	15	304	14	.366
Genito-urinary tract cancer	314	12	30	8	284	13	**.020**
Colorectal cancer	236	9	37	10	199	9	.378
Breast cancer	155	6	12	3	143	6	**.024**
Gynaecologic cancer	136	5	27	8	109	5	**.035**
Melanoma	106	4	13	4	93	4	.641
*Other cancers****	565	22	65	18	500	22	.075
Metastases[$]	240	9	42	12	198	9	.080
Specialist palliative care							
Early[c]	165	6	165	46			
Late[d]	194	7	194	54			
Very late[e]	433	17			433	19	
None	1811	70			1811	81	

[a] SPC initiated > 30 days before death. [b] SPC initiated ≤ 30 days before death or not at all. [c] initiated > 90 days before death. [d] initiated ≤ 90 days and > 30 days before death. [e] initiated ≤ 30 days before death. *based on registered ICD-10 code in the last year of life. **GI: gastro-intestinal. ***aggregated group of diagnoses: prevalence < 3% per diagnosis. [$] includes both unknown primary cancers and so-called malignancies of other secondary and unspecified sites.

Potentially inappropriate end-of-life care

Of all 2,603 patients, 690 (27%) experienced potentially inappropriate end-of-life care during the last 30 days of life; 19% in the exposure group (n=359) and 28% patients in the non-exposure group (n=2,244), (p< 0.001). Table 2 lists the six quality indicators for potentially inappropriate end-of-life care. ICU-admission (1% vs 7%, p< 0.001) and hospital death (6% vs. 18%, p< 0.001) occurred less often in the exposure group compared to the non-exposure group.

Timing of SPC

In the exposure group, SPC was initiated early (>90 days before death) in 46% (Table 3). Patients receiving early SPC had a mean total of 7 consultations before death and patients receiving late SPC had 5. No differences in prevalence of potentially inappropriate end-of-life care or mean number of individual quality indicators per patient were found between patients receiving early or late SPC.

Table 2. Quality indicators of potentially inappropriate end-of-life care[a].

Characteristic	**Total population**		**Exposure group**		**Non-exposure group**		**p-value**
	N	%	N	%	N	%	
Overall no. of decedents	2,603	100	359	14	2,244	86	
Inappropriate EoL[b] care[c]							
Yes	690	27	68	19	622	28	**< .001**
No	1,913	73	291	81	1,622	72	
Indicators							
≥ 2 emergency room visits	115	4	15	4	100	5	.812
≥ 2 hospital admissions	244	9	32	9	212	9	.747
> 14 days of hospitalisation	200	8	22	7	178	8	.233
Chemotherapy	112	4	16	5	96	4	.877
ICU admission	157	6	4	1	153	7	**< .001**
Hospital death	430	17	21	6	409	18	**< .001**
Mean composite score (SD)[d]	1.8 (.96)		1.6 (.93)		1.8 (.96)		.064
First initiation of SPC[e] (mean)[f]	1.8		3.7		0.3[g]		

[a] in the last 30 days before death. [b] EoL; end-of-life. [c] qualification is rendered positive when 1 out of 6 indicators is scored. [d] total amount of 6 indicators divided by number of patients receiving potentially inappropriate end-of-life care. [e] SPC; specialist palliative care. [f] in months before death. [g] based on 433 patients with very late SPC (initiated ≤ 30 days before death (Table 1)).

Table 3. Quality indicators for potentially inappropriate end-of-life care[a] in the **exposure group** (n= 359) in relation to **timing of palliative care**.

Characteristic	**Early SPC**[b]		**Late SPC**[c]		**p-value**
	N	%	N	%	
Overall no. of decedents	165	46	194	54	
Inappropriate EoL[d] care[,e]					
Yes	29	18	39	20	.542
No	136	82	155	80	
First initiation of SPC (mean)[g]	5.9		1.8		
Number of SPC consultations > 3 months[h]	2 (1-3)		-		
Number of SPC consultations 3-1 month[s]h	2 (1-4)		2 (1-3)		
Number of SPC consultations < 1 month[h]	3 (2-4)		3 (1-4.5)		

[a] in the last 30 days before death. [b] early specialist palliative care; initiated > 90 days before death. [c] late specialist palliative care; initiated ≤ 90 days and > 30 days before death. [d] EoL; end-of-life. [e] qualification is rendered positive when 1 out of 6 indicators is scored. [f] total amount of 6 indicators divided by no. patients receiving potentially inappropriate EoL care. [g] in months before death. [h] median and interquartile range.

Initial setting of SPC provision

In the exposure group, 26% of SPC provision was initiated in the outpatient setting (Table 4). Patients for whom palliative care was initiated in the inpatient setting more often received potentially inappropriate end-of-life care compared to those for whom it was initiated in the outpatient setting, respectively 22% vs 12%, (p= .037). On average, SPC was initiated 4.4 months before death in the outpatient group and 3.4 months in the inpatient group.

Table 4. Quality indicators for potentially inappropriate end-of-life care[a] in the **exposure group** (n= 359) in relation to **initial setting of palliative care**.

Characteristic	Outpatient		Inpatient		p-value
	N	%	N	%	
Overall no. of decedents	94	26	265	74	
Inappropriate EoL[b] care[c]					
Yes	11	12	57	22	**.037**
No	83	88	208	78	
First initiation of SPC (mean)[e]	4.4		3.4		

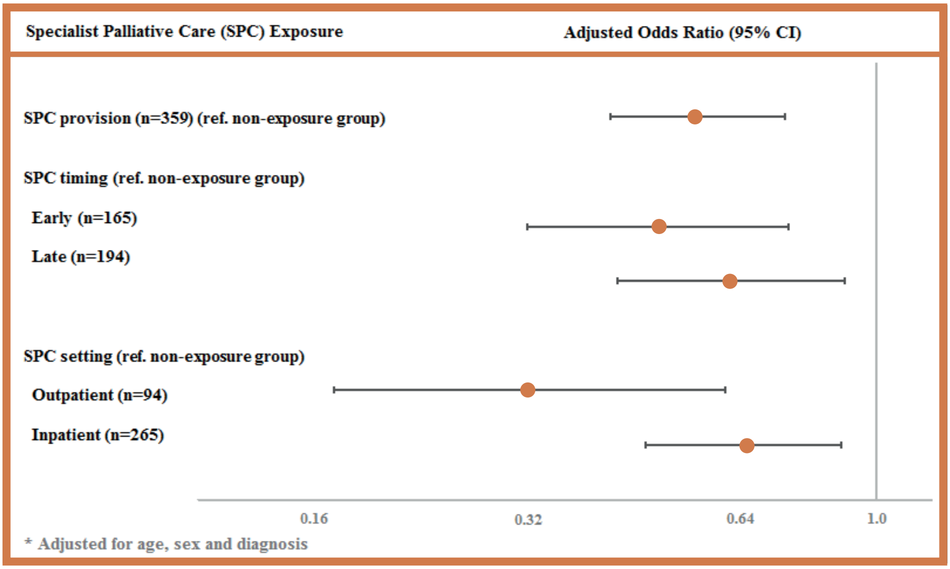
[a] in the last 30 days before death. [b]EoL; end-of-life. [c]qualification is rendered positive when 1 out of 6 indicators is scored. [d]total amount of 6 indicators divided by number of patients receiving potentially inappropriate end-of-life care. [e]in months before death.

Association between provision, timing and setting of SPC and receiving potentially inappropriate end-of-life care.

Adjusted for age, sex and cancer diagnosis, patients receiving SPC more than 30 days before their death (exposure group) were nearly two times less likely to experience potentially inappropriate end-of-life care (adjusted OR 0.55; 95% CI 0.42 to 0.74) compared to patients who received no SPC or received SPC less than 30 days before their death (non-exposure group).

Subgroup analysis of the exposure group showed similar odds for both early (>90 days) and late (>30 and $\leq$90 days) SPC initiation (AOR 0.49; 95% CI 0.32 to 0.75 and 0.62; 95% CI 0.43 to 0.90, respectively) as for inpatient initiation (AOR 0.65; 95% CI 0.47 to 0.89) compared to the non-exposure group (Figure 2). Patients for whom SPC was initiated in the outpatient setting appeared three times less likely to receive potentially inappropriate end-of-life care compared to the non-exposure group (AOR 0.32; 95% CI 0.17 to 0.61).

Figure 2. Association between specialist palliative care and potentially inappropriate end-of-life care.*



* Adjusted for age, sex and diagnosis

Discussion

This study showed that more than one fourth of deceased patients with cancer in two acute care hospitals in the Netherlands receive potentially inappropriate care in their last month of life. Of all deceased patients with cancer nearly one third receives specialist palliative care, of which 13% receives it prior to the last month of life. Patients who receive SPC before their last month of life are nearly two times less likely to experience potentially inappropriate care in the last month of their lives compared to patients who receive no SPC or receive it only in their last month of life. Our results suggest that initiation of SPC provision in the outpatient setting might further enhance these odds, whereas the majority of patients receives SPC in the inpatient setting.

Remarkedly, the highest proportion of decedents in our study population consisted of patients with non-colorectal gastro-intestinal cancer (Table 1). This may be a result of the tertiary-referral capacity of the university medical centre involved in this study. Moreover, our data concern prevalent cancer diagnoses in deceased patients, which may differ from prevalence at diagnosis due to progressiveness of diseases. As the subsequent prevalence of cancer diagnoses in our data is in line with overall prevalence in the Netherlands, we believe our data can still be considered generalisable for comparison to other hospitals.[36]

Our results show an overall proportion of 30% of patients with advanced cancer received hospital-based SPC in the year prior to their death. In a previous population-based observational study we assessed national data across care settings and found that of all patients with cancer in the Netherlands who died in 2017, only 9% were provided with SPC in the year prior to their death, compared to 29% in Canada and 47% in Belgium.[25 26 27] In view of complex reimbursement regulations for hospital-based SPC teams and the observed low referral rates to these teams in a previous hospital survey,[19] under-registration and underutilisation of specialist palliative care were hypothesised to account for the low percentage of SPC provision and the high proportion (34%) of patients receiving potentially inappropriate end-of-life care in this study.

As reimbursement regulations have since been changed and our current results show a higher proportion of SPC provision, under-registration may well have contributed to prior results.[25] However, our findings mainly support the hypothesis of general underutilisation of SPC in our previous study, as our current study shows a higher degree of hospital-based SPC utilisation is associated with a lower proportion of patients receiving potentially inappropriate end-of-life care (27%).

In a systematic literature review and meta-analysis addressing the association between palliative care and patient and caregiver outcomes, palliative care was consistently associated with lower healthcare utilisation as well as with improved patient and caregiver satisfaction.[37] In line with our findings, several studies have recently used administrative databases and demonstrated an association between palliative care and healthcare utilisation at the end of life, both for patients with cancer as for patients with non-cancer diseases.[25 27 28 30 38-40]

Addressing the effect of timing of palliative care provision on quality end-of-life indicators, a recent study indicated patients provided with either generalist or specialist palliative care more than one month before their death were less likely to be admitted or die in hospital.[28] These findings are in line with our current hospital-based study as well as our previous study across care settings.[25] Contrary to other studies, our study did not show significant improvement in quality of end-of-life care through earlier (>3 months) initiation of SPC.[12 13 28 40] This may be attributed to the relatively small number of patients in the early-late SPC analysis. However, these results are consistent with findings in our previous nationwide population-based study.[25]

While using similar definitions for early and late palliative care as previous studies, these studies did not exclude palliative care provided during the outcome period (i.e.,, last 30 days before death) from the late palliative care group.[12 13 40] This may have reflected positively on the outcomes for potentially inappropriate end-of-life care in patients with early SPC, as patients provided with SPC in the last 30 days before death may have more unstable conditions and would thus be more likely to receive acute hospital care at the end of life. Results from multiple randomised trials have also emphasised the positive effect of early SPC. However, in these studies SPC was not only initiated shortly after diagnosis of advanced cancer, it was also initiated in the outpatient setting.[9 10 41 42]

When looking at setting, in our study 26% of patients provided with SPC were initiated in the outpatient clinic. Adjusted for age, sex and diagnosis, these patients were three times less likely to receive potentially inappropriate end-of-life care compared to the non-exposure group. Although this analysis comprised a relatively small population, a previous study among 366 deceased patients assessing both early and outpatient SPC found that only outpatient SPC provision was independently associated with less potentially inappropriate end-of-life.[12] More recently, similar results were reported in a study of 327 patients where specifically SPC exposure in the outpatient setting was linked to shorter hospital length of stay and lower ICU admissions.[14]
Comparing inpatient and outpatient SPC, visits are characterised by marked differences: outpatient SPC visits are often a result of referral earlier in the disease course, enabling longitudinal building of rapport, patient and family coping skills, and disease understanding; whereas inpatient SPC referrals often occur later in the disease trajectory, usually providing assistance with acute symptom management and decision making in the context of hospitalisation or clinical crisis.[43] Our results suggest an importance for outpatient SPC involvement, as referral of patients to outpatient SPC prior to their last month of life appears to strengthen the odds for lower acute healthcare utilisation at the end of life.

Strengths and limitations

The use of electronic medical records covering all patients registered in the participating hospitals enabled us to assess the quality of end-of-life care for a cohort of patients. In addition, it minimised selection bias and rendered our findings generalisable for comparison to other hospitals treating patients with cancer. Designing a feasible data query tailored to answer the research aims required careful coding of the indicators and multiple checks for accuracy. To enable this process our multidisciplinary research team comprised data scientists, healthcare professionals, an epidemiologist and a reimbursement administrator. However, some limitations need to be addressed. Firstly, since population-based quality indicators are used on an aggregated level they cannot be used as indicators of inappropriate care for individual patients, where clinical factors may justify acute care interventions and personal preferences may differ. Therefore, we strictly adhered to the term ‘potentially’ inappropriate end-of-life care. Secondly, rather than prospectively collecting data to answer our research questions, we extracted our data retrospectively from administrative databases not primarily designed for the purpose of quality assessment. Therefore, a general limitation results from a lack of clinical information about the complexity of needs and content of care provided, the awareness of healthcare professionals about their patients being in their last months of life and whether patients ultimately died as a result of their cancer diagnosis or of other causes. Subsequently, we could not control for disease-related confounders such as performance status, illness severity or prior cancer treatment and confounding by indication may therefore be present.[44] Thirdly, we collected our data in just two acute care hospitals resulting in a limited number of patients. Finally, recent population-based studies have indicated that patients who received inpatient palliative care within six months prior to their death were more likely to access community palliative care after discharge than those who received no inpatient palliative care.[45 46] The receipt of community palliative care after hospital discharge has been shown to decrease readmissions and health care utilisation.[47 48] Therefore, outside the scope of this study, continuity of palliative care in the community may have added to our results.

Conclusion and policy implications

This study shows that referrals to specialist palliative care for patients with cancer mostly occur late in the disease trajectory and in the inpatient setting. Initiation of specialist palliative care prior to the last month of life is associated with less potentially inappropriate end-of-life care in the last month of life. Initiation in an outpatient setting may further enhance these odds. These results imply a need to improve access to specialist palliative care prior to the last month of life. Future research should examine differences in the underlying characteristics of early (>90 days before death) and late (≤90 and >30 days before death) as well as outpatient and inpatient specialist palliative care recipients to improve insight into the most effective model to provide SPC. This would allow for earlier identification of patients who may benefit from timely palliative care in a generalist-specialist palliative care model where referrals are based on complexity of palliative care needs instead of diagnosis or prognosis. In addition, further study of outpatient initiation of specialist palliative care may provide a better understanding of its benefits.

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Competing interest

None declared.

Licence of publication

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Supplement

Supplement table 1. DTC* - reimbursement codes for specialist palliative care provision.

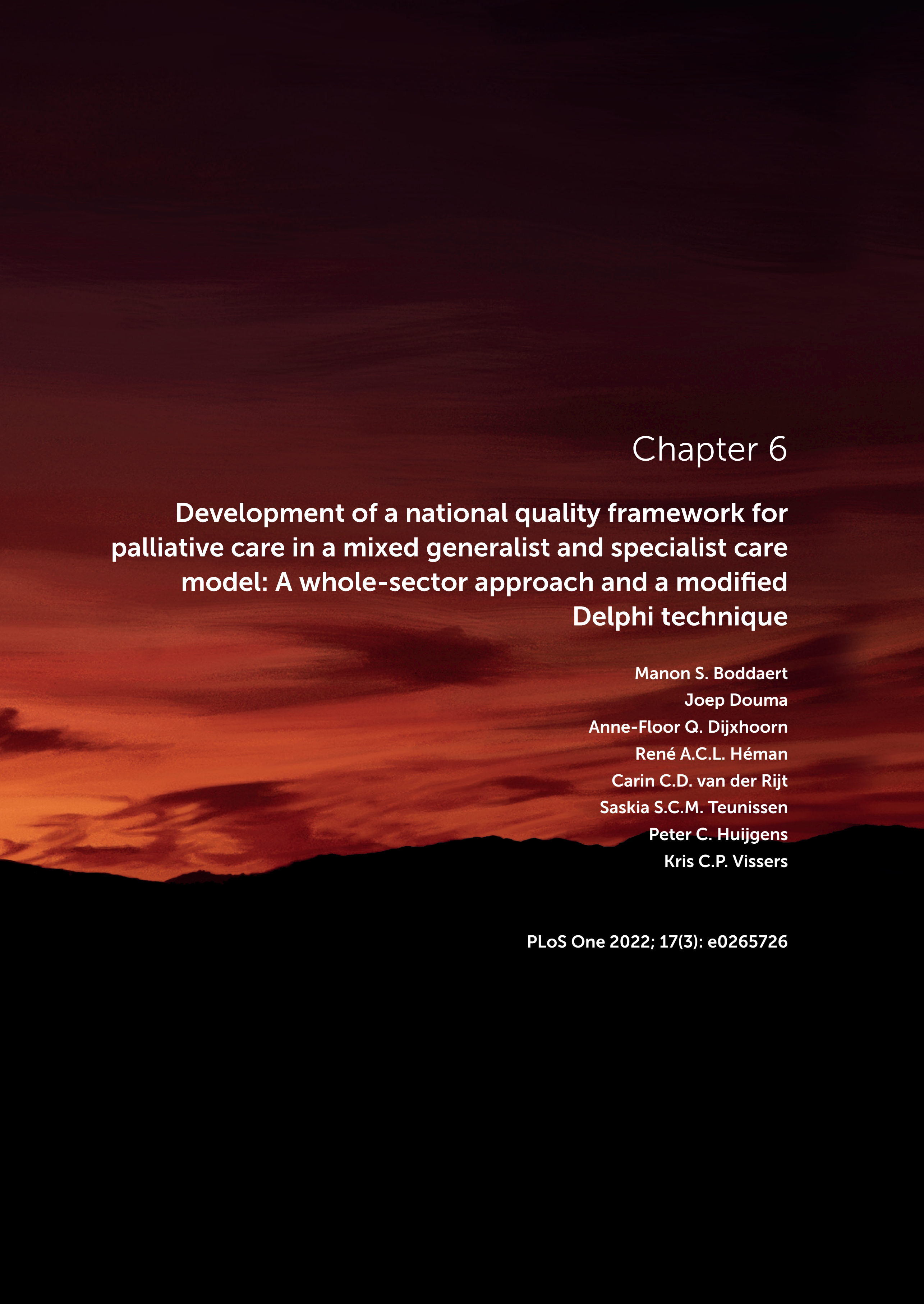
Reimbursement code specification	Code	Description	Billable for / by
Diagnosis	3130050	Palliative care	Internal medicine
Diagnosis	3309950	Palliative care	Neurology
Diagnosis	3890990	Palliative care	Anaesthesiology
Diagnosis	3229950	Palliative care	Pulmonary medicine
Diagnosis	3350352	Palliative care	Geriatric medicine
Consultation activity	190067	SPCT** consultation	Physician / NP$
Consultation activity	190006	SPCT meeting	Physician / NP
Consultation product	990040009	1-2 consultation(s)	Physician / NP
Consultation product	990040007	>2 consultations	Physician / NP
Consultation product	990040004	>1, with diagnostics	Physician / NP
Consultation product	990040006	>1, with procedure	Physician / NP
Consultation product	990040005	Day-care with procedure	Physician / NP
Consultation product	990040003	Admission	Physician / NP

*DTC: Diagnosis-Treatment Combination. **SPCT: Specialist palliative care team. $NP: Nurse practitioner.

Supplement table 2. SPCT*- appointment codes for specialist palliative care provision per hospital

Setting	Code	Description	Billable for / by
Inpatient	KEC	Initial consultation	SPCT general hospital
Inpatient	KVC	Follow-up consultation	SPCT general hospital
Outpatient	PEC	Initial consultation	SPCT general hospital
Outpatient	PVC	Follow-up consultation	SPCT general hospital
Interdisciplinary	ICC	Consultation between peers	SPCT general hospital
Inpatient	KNP	Initial consultation physician	SPCT university hospital
Inpatient	KNPVC / VS	Initial consultation nurse / NP**	SPCT university hospital
Inpatient	KCO	Follow-up consultation physician	SPCT university hospital
Inpatient	KCOVC / VS	Follow-up consultation nurse / NP	SPCT university hospital
Outpatient	NP	Initial consultation physician	SPCT university hospital
Outpatient	NPVC / VS	Initial consultation nurse / NP	SPCT university hospital
Outpatient	CO	Follow-up consultation physician	SPCT university hospital
Outpatient	COVC / VS	Follow-up consultation nurse / NP	SPCT university hospital
E-consult	TP	Phone / E-consultation physician	SPCT university hospital
E-consult	TPVC / VS	Phone / E-consultation nurse / NP	SPCT university hospital
Interdisciplinary	ICC	Consultation between peers	SPCT university hospital

*SPCT: Specialist palliative care team.**NP: Nurse practitioner.



Chapter 6

Development of a national quality framework for palliative care in a mixed generalist and specialist care model: A whole-sector approach and a modified Delphi technique

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Abstract

Background

In a predominantly biomedical healthcare model focused on cure, providing optimal, person-centred palliative care is challenging. The general public, patients, and healthcare professionals are often unaware of palliative care's benefits. Poor interdisciplinary teamwork and limited communication combined with a lack of early identification of patients with palliative care needs contribute to sub-optimal palliative care provision. We aimed to develop a national quality framework to improve availability and access to high-quality palliative care in a mixed generalist-specialist palliative care model. We hypothesised that a whole-sector approach and a modified Delphi technique would be suitable to reach this aim.

Methods

Analogous to the international AGREE guideline criteria and employing a whole-sector approach, an expert panel comprising mandated representatives for patients and their families, various healthcare associations, and health insurers answered the main question: 'What are the elements defining high-quality palliative care in the Netherlands?'. For constructing the quality framework, a bottleneck analysis of palliative care provision and a literature review were conducted. Six core documents were used in a modified Delphi technique to build the framework with the expert panel, while stakeholder organisations were involved and informed in round-table discussions.

Results

In the entire process, preparing and building relationships took one year and surveying, convening, discussing content, consulting peers, and obtaining final consent from all stakeholders took 18 months. A quality framework, including a glossary of terms, endorsed by organisations representing patients and their families, general practitioners, elderly care physicians, medical specialists, nurses, social workers, psychologists, spiritual caregivers, and health insurers was developed and annexed with a summary for patients and families.

Conclusion

We successfully developed a national consensus-based patient-centred quality framework for high-quality palliative care in a mixed generalist-specialist palliative care model. A whole-sector approach and a modified Delphi technique are feasible structures to achieve this aim. The process we reported may guide other countries in their initiatives to enhance palliative care.

Introduction

Palliative care aims to improve the quality of life of patients, and their families, who are facing problems associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification, impeccable assessment, and the treatment of pain and other physical, psychosocial, and spiritual problems.[1] Palliative care is frequently delivered by generalists in palliative care, for issues such as advance care planning in a primary care setting or symptom management in secondary care.[2 3] In addition, multidisciplinary specialist palliative care teams deliver care for more complex needs in inpatient, outpatient, or community-based service models.[4 5]

However, within a predominantly biomedical healthcare model focused on cure, it is challenging to provide optimal, person-centred palliative care grounded in comfort and dignity.[6-9] The general public, patients, and healthcare professionals are frequently unaware of the benefits of palliative care and how and when to access it.[10 11] Moreover, patients in a palliative care trajectory face challenges brought about by the disease as well as by complicated and fragmented healthcare systems, which require coordination between healthcare professionals, various healthcare settings, and diagnostic and treatment interventions.[12-14] Additionally, most healthcare professionals lack sufficient training and skills in symptom management, communication, and care coordination.[15 16] Poor interdisciplinary teamwork and limited communication combined with a lack of early identification of patients with palliative care needs contribute to the provision of sub-optimal palliative care.[17-19] Therefore, patients in a palliative care trajectory continue to receive inappropriate treatments at the end of their lives, often leading to poor quality and high-cost care.[6 20 21] This is despite evidence that the early integration of generalist and specialist palliative care improves symptoms, the quality of life, and quality of care for these patients.[22-30] and notwithstanding professional organisations' recommendations for earlier and routine co-management by palliative care specialists.[31-33]

In 2014, the World Health Organisation (WHO) called for standardised availability, equitable access, and high-quality palliative care as a human right and the strengthening of generalist and specialist palliative care as a component of integrated care throughout the patient's life.[34] In high-income countries, approximately 75% of people approaching the end of their lives could benefit from palliative care and even more are expected to need palliative care in the future.[35-37] To anticipate this foreseen increase, and an unforeseen tsunami of suffering as witnessed during the COVID-19 pandemic, healthcare systems need to focus on the integration of palliative care across all levels of health and social care disciplines, while preparing and training all healthcare professionals to deliver generalist palliative care.[3 4 38-41]

In the Netherlands, national palliative care programmes have been part of the government's health policy since 2007, and a white paper and a standard for palliative care have since been developed.[42 43] However, concerns regarding life-prolonging treatments prevailing over comfort-oriented care near the end of life remain.[44] With the intent to improve availability and access to high-quality palliative care for all people with life-threatening illnesses, we developed a national consensus-based quality framework for the optimal organisation and delivery of patient-centred palliative care in a mixed generalist and specialist palliative care model.[45] We hypothesised that a whole-sector approach and a modified Delphi technique could be beneficial for the broad recognition and integration of palliative care.[19 46] The process of development and consensus-building and its key elements are presented here.

Methods

For the development of this national quality framework for palliative care, we adhered to the Guideline for Guidelines.[47] a complementary tool to the revised international criteria for Appraisal for Guidelines of Research and Evaluation (AGREE II).[48] Considering the broad scope and the multidisciplinary nature of palliative care as well as an extensive amount of stakeholders, we employed a whole-sector approach.[19] and consulted an expert panel in a modified Delphi technique to answer the research question.[49-51] We structured the development into three phases: Preparation, development, and finalisation (Fig 1).

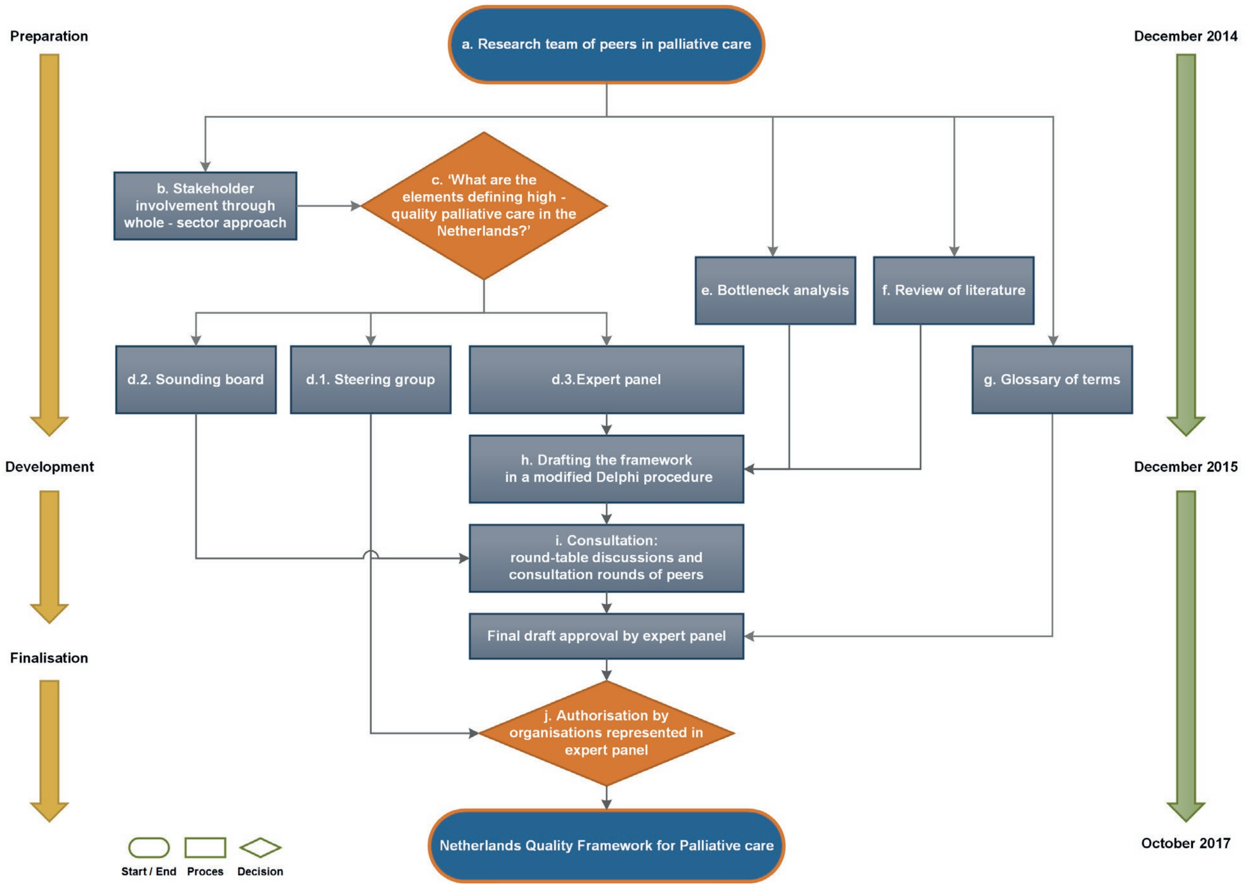


Fig 1. Structure and process to develop the quality framework. *Letters a-j refer to subheadings in text.*

Preparation – building consensus and an organisational structure

a. Research team of senior peers in palliative care

Late 2014, a research team of senior peers in palliative care (senior physicians in palliative care and medical oncology) representing the Dutch Society of Professionals in Palliative Care (Palliactief) and the Netherlands Comprehensive Cancer Organisation (IKNL), initiated the development of the Netherlands Quality Framework for Palliative Care (NQFPC). The role of the research team consisted of planning and managing the overall project, consulting and informing the stakeholders and processing the results from the Delphi rounds to inform each next step in the process.

b. Stakeholder involvement

The research team consulted 26 stakeholder associations and organisations. In line with a whole-sector approach, they represented various medical, nursing, and allied health professional disciplines, patients, informal caregivers, volunteers, health insurers, healthcare umbrella organisations, hospice care organisations, and policymakers (Supplement table 1). In personal interviews, the research team explored their views on the need for and their willingness to contribute to the development of a national consensus-based quality framework in order to obtain whole-sector support.

c. Main question

Broad consent was acquired, and stakeholders agreed to answer the main question: ‘What are the elements defining high-quality palliative care in the Netherlands?’

d. Structure for the development of the NQFPC

To answer this main question, the consulted stakeholder organisations were invited to participate in: 1) a steering group (organisations representing the patient population, the targeted users of the quality framework, and health insurers) or 2) a sounding board (organisations representing patients with specific diagnoses, hospice care organisations, policymakers, research institutes, among others), to support 3) an expert panel for the duration of the development process.

This multidisciplinary expert panel represented patients, healthcare providers, and health insurers, and was formed to draft the content of the NQFPC. Ten members of the expert panel represented the targeted users of the quality framework and originated from all regions of the Netherlands – various types of hospitals, relevant care settings, and disciplines. They had either generalist or specialist expertise in palliative care, in addition to expertise in anaesthesiology/pain medicine, internal medicine, medical oncology, geriatrics, primary family healthcare, elderly healthcare, nursing, psychology, social care, and spiritual care and were mandated by their national organisations to provide their inputs. Two members of the expert panel were representatives of patients. To ensure that the content of the NQFPC would primarily be care- and quality-driven and that costs-related interests would be secondary, the representative of all Dutch health insurers did not participate in expert panel meetings but provided input in subsequent separate meetings with the research team.

Development – the process of drafting the content

e. Bottleneck analysis

For the NQFPC to improve the accessibility and availability of high-quality palliative care, perceived bottlenecks or barriers in palliative care practice needed to be identified in order to be addressed in the quality framework. Therefore, a search of Dutch palliative care literature published between 2005 and 2015 was performed.[52] Furthermore, a national survey assessing the organisation and quality of specialist palliative care in hospitals was conducted. The results of both were discussed in an invitational conference with representatives from medical and nursing organisations in primary care, initiated by the Royal Dutch Medical Association. Attendees were asked to (1) indicate whether they agreed with the identified barriers; (2) suggest potential solutions for daily practice; and (3) indicate additional problems.[52]

f. Review of literature

The aim of the literature review was to identify international quality reports, guidelines, frameworks, and standards for palliative care that could serve as core documents for the development of the Dutch quality framework. Search terms consisted of 'quality standards AND palliative care AND hospice care'. As PubMed and Google Scholar hardly provide results for published standards of care, we performed our search in the Google database.[53] Titles were screened as the first step in the assessments of potentially relevant results. Subsequently, reports, guidelines, frameworks, and standards describing criteria for palliative care were included and manuscripts, books, and websites were excluded. The remaining documents were evaluated by their cover page and included according to the date of publication (between 2005 and 2015), and when publications were in English, documents originated from high-income countries, and the content had a national scope. Subsequently, documents were analysed and those with abstracts or summaries referring to all patients with palliative care needs (i.e.,, they were not limited to specific diseases or patient-groups) and with cross-references to scientific literature were included. Finally, the content of the remaining documents was reviewed to ascertain whether it comprised the entire scope of palliative care and was applicable to the Dutch healthcare setting. A similar strategy was employed for a review of national literature.

g. Glossary of terms

During stakeholder consultations, it became apparent that a mutual understanding of terminology was needed. Therefore, a glossary of terms was added to the quality framework. While constructing the framework, terms for which clarification was deemed important were identified. Definitions of these terms were searched in national and international literature. When no definition seemed available, or if it did not fit the context of the quality framework, experts in the discipline concerned were consulted to formulate a consensus-based definition or description of the term.

h. Drafting the quality framework in a modified Delphi procedure

To answer the research question, we used a modified Delphi technique among the members of the expert panel. This technique is based on gathering the experts together and discussing the issues from a Delphi survey round in a structured way to reach consensus among all participants simultaneously. Thus, the modified Delphi technique can achieve consensus in a more time- and cost-effective manner.[50] We alternated two written Delphi survey rounds with face-to-face meetings of the expert panel.[49-51]

Analogous to the predominant structure of the core documents, the expert panel constructed the quality framework using domains, standards, and criteria. Each domain described a dimension of palliative care and consisted of one or several standards indicating best practice, supported by several criteria on how to achieve these standards. For each domain, expert panel members were invited to suggest additional national literature that could aid in tailoring the quality framework to the Dutch healthcare system.

- *Data extraction:*

In the initial face-to-face meeting with the expert panel, the selected core documents from the literature review were presented and the format for informational input in the Delphi survey rounds was piloted for clarity and feasibility. For each domain, the research team selected all relevant standards from the core documents, aligned all supporting criteria, and presented them to the expert panel in a first Delphi round (Supplement table 2). Each panel member was asked to indicate which of the standards and criteria should be included in the quality framework. Using standardisation percentages, each standard and criterion was graded for admission (> 66% agreed), discussion (50%-66% agreed), or dismissal (<50% agreed).

- *Data synthesis:*

From the results of the first Delphi round, the research team constructed each domain with the standards and criteria that were accepted or needed to be discussed. Subsequently, the selected standards and criteria were extensively discussed in intermediate face-to-face meetings with all expert panel members and either accepted, discarded, revised, or adapted to the Dutch context. The representatives of patients in the expert panel had the decisive vote whenever a consensus could not be reached.
As a next step, the research team processed the results from the face-to-face meetings and issued a second Delphi round with the expert panel for iterative feedback.

Finalisation

i. Consultation

The research team organised two round-table discussions to inform and involve the steering group and sounding board in the drafting process. Both round-table discussions were followed by written consultation rounds among peers to gather feedback on draft recommendations and assess applicability in clinical practice. These consultation rounds were issued at the same time as the second Delphi round with the expert panel.

j. Authorisation

After processing feedback from the second Delphi round and the consultation round and obtaining the approval of the final draft of the NQFPC, including its glossary of terms, in a last meeting with the panel members, it was submitted to the associations and organisations represented in the expert panel for final review and authorisation or approval.

Results

It took the research team one year of preparation and building of stakeholder relationships to acquire broad consent for the development of the NQFPC from the whole sector involved in palliative care while simultaneously performing a bottleneck analysis and reviewing literature for core documents (Fig 1). In addition, slightly over 18 months were dedicated to the surveying of and convening with the expert panel, writing the NQFPC drafts, discussing content, consulting peers, and obtaining final consent from everyone involved. For clarity, our results focus on the process of defining and finalising the content of the NQFPC.

Development – the process of defining the content

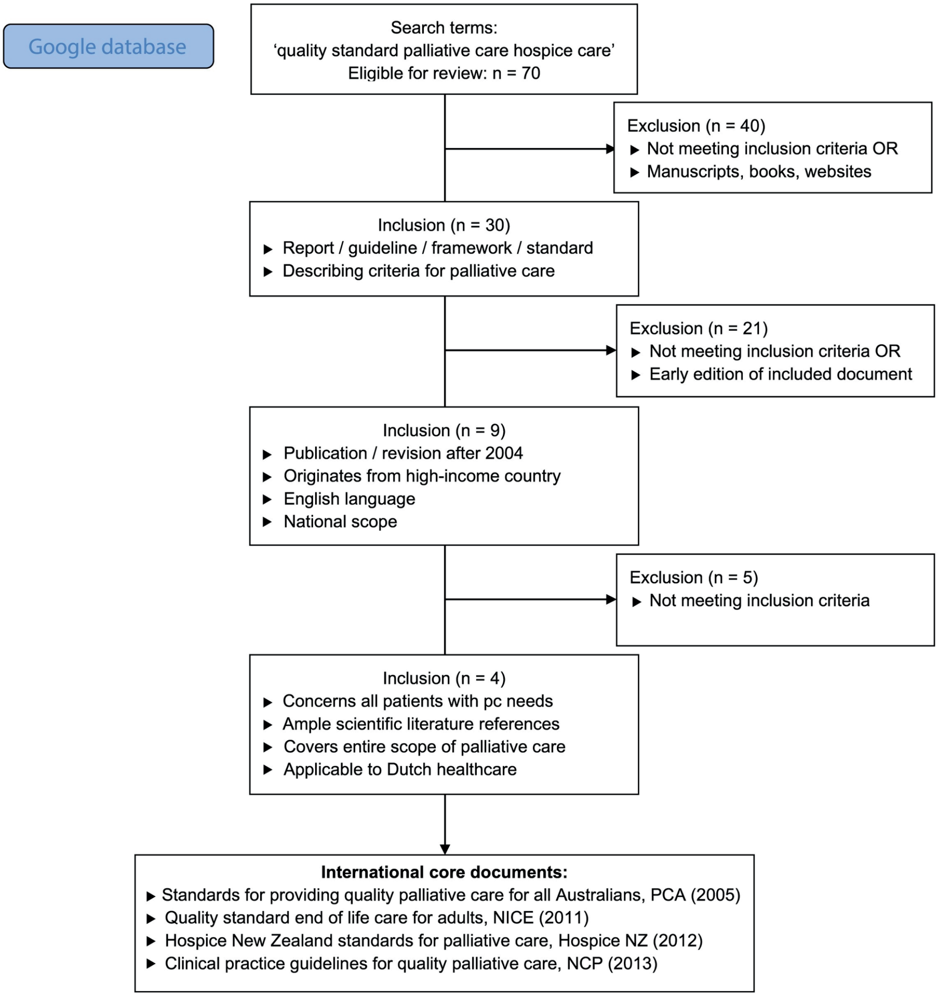
Bottleneck analysis

The main barriers identified as elements for improvement in the organisation and delivery of palliative care were: 1) information and communication about prognosis, treatment options, and the end of life, 2) coordination and the continuity of care, 3) expertise, education, and training of healthcare professionals, and 4) rules, regulations, and reimbursement (Supplement table 3). The first three barriers were identified by both patients and healthcare professionals and were addressed throughout the construction of the NQFPC. The last barrier was predominantly reported by healthcare professionals and was addressed separately in a supplementary guide.[54] The full results from the hospital survey and the bottleneck analysis are presented elsewhere.[16 52 55]

Review of literature

The predefined search terms yielded 680,000 results in the Google database. The first 70 titles were considered eligible for initial review, as the relevance of titles increasingly diminished until the saturation of relevant results occurred. Subsequently, 40 manuscripts, books, and websites were excluded and 30 reports/guidelines/frameworks/standards describing criteria for palliative care were included (Fig 2). Assessment of the remaining documents according to the predefined procedure resulted in four international documents with content applicable to the Dutch healthcare setting and which comprised the entire scope of palliative care. A similar strategy was used to review Dutch literature. The initial search yielded 28,000 results. After applying the predefined steps to 70 initial titles, two Dutch documents remained. Consequently, four international and two national documents formed the core documents for the development of the NQFPC.[43 56-60]

Fig 2. Flow diagram for the review of international literature.



Glossary of terms – definition of palliative care

A glossary of terms was annexed to the NQFPC. Definitions of 82 terms that were identified as requiring clarification were searched and found mostly in national and international literature. Since consensus on the definition of palliative care was an important starting point to answering the main question, extensive attention was paid to it at the start of the process.

Both the expert panel and their peers (in consultation rounds) extensively discussed the 2002 WHO definition of palliative care.[1] First, this definition was compared to numerous other definitions from international literature, particularly the one used in the National

Consensus Project for Quality Palliative Care (2013).[59 61-63] Unlike the WHO definition, this definition explicitly cited aspects of palliative care that were considered important in Dutch culture, such as interdisciplinary collaboration, dignity, autonomy, access to information, and the opportunity to make choices.[64] Conversely, the WHO definition clearly lays more emphasis on the importance of early identification. Second, the expert panel re-examined the concept of a life-threatening condition. The prevailing view was that this description did not sufficiently reflect the current diversity of the targeted patient groups within palliative care and particularly failed to include the concept of frailty. Finally, we considered it relevant to the definition that palliative care in the Netherlands is mostly delivered by generalists or non-specialists in palliative care, who receive support from specialists in palliative care when required. The expert panel ultimately agreed to add these important points for palliative care, in the Netherlands, to the WHO definition (Fig 3).

Fig 3. Palliative care as defined in the quality framework (adapted from WHO, 2002).

Palliative care is care improving the quality of life of patients and their families, who are facing a life-threatening condition or frailty, through prevention and relief of suffering by means of early identification and careful assessment, and treatment of problems of a physical, psychological, social and spiritual nature. Over the course of the illness or frailty, palliative care aims to preserve autonomy, access to information and the opportunity to make choices.

Palliative care has the following characteristics:

- care can be given concurrently with disease-oriented treatment;
- generalist healthcare 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;
- to ensure continuity, care is coordinated by a central healthcare professional;
- the wishes of patients and their families concerning dignity are acknowledged and supported throughout the illness or frailty, during the process of dying and after death.

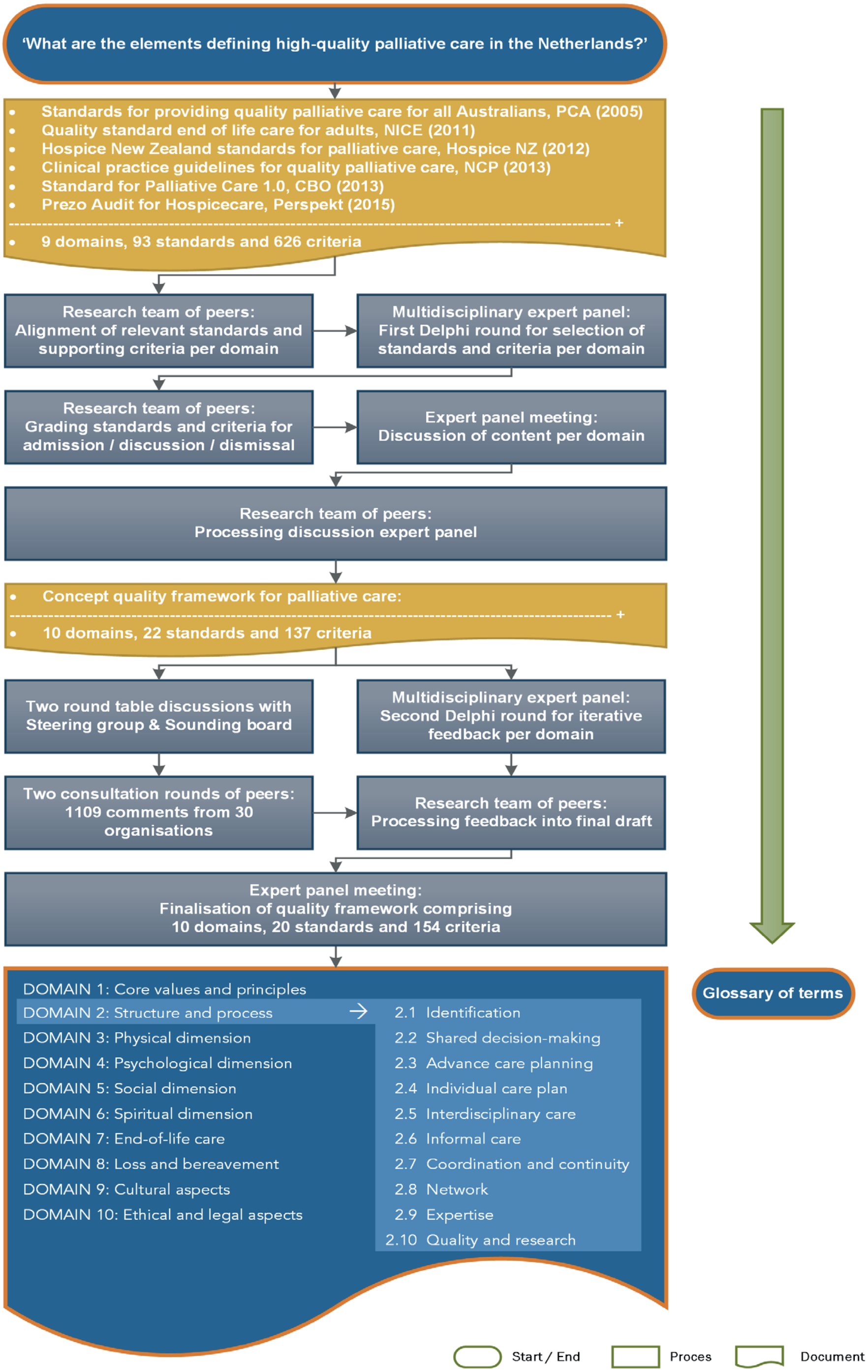
Drafting the framework in a modified Delphi procedure

The initial expert panel meeting focused primarily on evaluating and discussing the WHO definition of palliative care (Fig 3). Additionally, based on the predominant structure of the core documents, they agreed that the NQFPC should comprise nine domains consisting of standards and criteria, which together cover the entire spectrum of care for patients with a life-threatening illness or frailty and their families. These specific domains were to be preceded by a primary domain that addresses the 'core values and principles' of palliative care (Fig 4). Moreover, the expert panel members unanimously agreed to base the NQFPC on the values, wishes, and needs of patients and their families and address the barriers that had resulted from the bottleneck analysis. Furthermore, they suggested prioritising the standards and criteria specifically aimed at resolving these barriers as key elements for integration.

Data extraction and synthesis

The research team extracted 9 domains, 93 standards, and 626 criteria from the core documents and aligned relevant standards and criteria per domain for evaluation by each expert panel member. Based on the results from the first Delphi round, the research team constructed each domain with the standards and criteria that were either accepted by expert panel members (> 66% agreed) or needed to be discussed (50%–66% agreed). The constructed domains were evaluated and discussed, and the selected standards and criteria were either accepted, discarded, revised, or adapted to the Dutch situation across five expert panel meetings. The patients' representatives attended all expert panel meetings, actively participated in the discussions, and optimised the formulation of the patient's perspective in the draft texts. The first NQFPC draft consisted of 10 domains, 22 standards, and 137 criteria.

Fig 4. Developing the content of the quality framework including a glossary of terms.



Finalisation

Consultation and authorisation

In concurrence with the second Delphi round, two round-table discussions with the steering group and the sounding board followed by written consultation rounds with peers (Fig 4) yielded 1,109 comments from 30 organisations, which were processed by the research team. In the last expert panel meeting, the final draft consisting of 10 domains, 20 standards, and 154 criteria was approved by all expert panel members. It was subsequently submitted for authorisation or approval to the associations and organisations represented in the expert panel. The NQFPC was endorsed by eight branches and umbrella organisations and was published online in October 2017. The complete framework has been translated into English and is freely available at www.palliaweb.nl/publicaties/netherlands-quality-framework-for-palliative-care.

With the help of the patients' representatives, a Netherlands Patients Federation editor, the Royal Dutch Medical Association, and the Netherlands Association for Palliative Care, the content of the quality framework was 'translated' into an e-book for patients.[65] This information is available at palliatievezorg.patientenfederatie.nl, a national website that provides information about palliative care for patients. The key elements (Table 1) were recommended as priorities for integration. In adherence to the Guideline for Guidelines.[47] the NQFPC is intended to be updated within five years.

Table 1. Key elements in the quality framework that address barriers from the bottleneck analysis.

Barrier	Key element*	Originating Domain in NQFPC
Information and communication (prognosis, treatment, end of life)	Effective Communication	1. Core values & Principles
	2.1 Identification	
	2.2 Shared Decision Making	2. Structure & Process
	2.3 Advance Care Planning	
Coordination & continuity of care	2.4 Individual Care Plan 2.7 Coordination & Continuity	2. Structure & Process
Expertise, education and training of healthcare professionals	Work – Life Balance	1. Core values & Principles
	2.9 Expertise	2. Structure & Process

*A key element consists of a specific standard and their affiliated criteria as described in the NQFPC (numbers in this table correspond to numbers in Fig 4.)

Discussion

A national quality framework for palliative care seemed an essential step to optimise palliative care for the increasing numbers of patients in a highly fragmented health care system that focuses on cure rather than care. We aimed at a whole-sector approach to obtain broad consent and recognition for high-quality, patient-centred palliative care that could be integrated across health care settings. By inviting patients, healthcare professionals from various medical, nursing, and allied disciplines, health insurers, and policymakers to participate and by building this framework with a modified Delphi technique along the international AGREE II criteria, we combined the aspirations, information, resources, knowledge, and skills of all stakeholders with a scientifically sound structure and reached consensus for the NQFPC that we believe none of the parties concerned could have achieved independently.[48 49 66 67]

The NQFPC aims to improve the availability of equitable access to high-quality palliative care for all people with life-threatening illnesses or frailty and their families. As identified by both patients and healthcare professionals in our bottleneck analysis (Supplement table 3), barriers to achieving the above-stated standards are frequently recurring themes in international literature.[12 68-74] In adherence to patients' values, wishes, and needs,[70-72 75] we selected the standards in the NQFPC that address these barriers as key elements for integration (Table 1) and recommended their prioritised integration in clinical practice: 1) early identification of patients in a palliative care trajectory,[18] 2) shared decision making and advance care planning,[69 70 72] 3) coordination and continuity of care, including an (electronically available) individual care plan,[12 68 74] 4) education and training of healthcare professionals,[15] including effective communication,[69] and learning how to cope with the emotional impact of providing palliative care in order to maintain a healthy work-life balance.[76]

From their initial involvement with the development of the NQFPC, the national government has been supportive of integrating the recommended key elements into regular healthcare. A national public health campaign was initiated to raise awareness for palliative care and its benefits for seriously ill people. Furthermore, the Netherlands Organisation for Health Research and Development (ZonMw) began assessing requests for the funding of palliative care projects based on their relevance to the integration of key elements. It has since funded the whole-sector development of an educational framework for palliative care across all levels of healthcare education to prepare and train all future healthcare professionals in generalist palliative care.[77] In addition, it supported the development of a national information database to evaluate the quality of end-of-life care and establish best practice performance standards in the near future. Currently, the Royal Dutch Medical Association has adopted guardianship of the NQFPC, and various medical associations plan a step-by-step integration. Moreover, because of the

NQFPC development process, we were able to apply a similar approach to developing a multidisciplinary guideline for advance care planning across healthcare settings during the COVID-19 pandemic.[78 79] Considering these developments, we conclude that using the structure of a whole-sector approach and a modified Delphi technique not only brought broad consensus for the NQFPC content but also contributed to the awareness, recognition, and integration of palliative care in public health.

Comparing the final content of the NQFPC to the four international core documents we used in the Delphi procedure confirms that the barriers established in our bottleneck analysis are similarly perceived internationally.[56-59] All four documents address the importance of early identification, shared-decision making and care planning, coordination of care, and the training of healthcare professionals. Similar to the NQFPC, all three Anglo-Saxon documents were aimed at both generalists and specialists in palliative care and volunteers, whereas the framework from the United States (US) mainly addressed specialists in palliative care. We incorporated the structure and part of the definition of palliative care from the US framework, built a glossary of terms similar to the New Zealand document, and shared the comprehensiveness and the whole-sector approach with the Australian framework. In addition, we deemed it appropriate to address advance care planning as an individual standard in the NQFPC, as it is Dutch government policy to facilitate 'dying in the patient's preferred location' for all citizens.[64]

Strengths and limitations

In addition to the strength of a whole-sector approach, we believe that building a research team with dedicated senior physicians in palliative medicine and medical oncology was critical to facilitate the entire process. This assured the analysis of the core documents to be grounded in appropriate clinical practice and expert panel meetings to be focused on content and the organisation of palliative care. Moreover, the ease of peer consultations when the need occurred enabled us to retain ongoing support from the required medical associations and healthcare organisations. However, some limitations of the project need mentioning. Although we described the 'what' elements and defined the optimal organisation and delivery of high-quality palliative care, we did not address 'how' these elements can be realised in clinical practice or what conditions are required to build a sustainable generalist and specialist palliative care service model.[3] Similar to the Anglo-Saxon quality frameworks, the next edition of the NQFPC may be extended with clear criteria and training requirements for specialists in palliative care.[56-58] This will aid the integration and availability of palliative care by enabling workforce planning and allowing for clear and efficient interdisciplinary cooperation and reimbursement structures.[2 80] Second, while stakeholders concerned with palliative care for people with special needs did participate as a sounding board, we limited the scope of this primary edition of the NQFPC and did not specifically address these populations. In view of equitable access to palliative care, the scope of the next edition of the NQFPC needs to include them.

While a substantial body of evidence exists to support clinical practice for quality palliative care, the quality of evidence is still limited. Hence, whether the integration of the key elements of the NQFPC in clinical practice will effectively diminish the perceived barriers for patients in a palliative care trajectory and their families is a subject that needs to be addressed through future research.

Conclusions

A whole-sector approach using the international AGREE II criteria and a modified Delphi technique to define the content is a feasible, effective, and efficient way to develop a national consensus-based patient-centred quality framework for high-quality palliative care. Considering the call to action from the WHO, the process described in this study contains potentially transferable information on how to develop such a framework by taking an inclusive approach and involving stakeholders from civil society rather than regarding palliative care merely as a medical discipline. As such, it may guide other countries' initiatives to improve the accessibility and availability of palliative care and can contribute to the recognition and integration of such care in public health.

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Competing interests

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Supporting Information

S 1. Stakeholder associations and organisations involved in whole-sector development of the Netherlands Quality Framework for Palliative Care

STEERING GROUP
Branch association for nursing homes, home care, rehabilitation care and youth welfare services (Actiz)
Netherlands Comprehensive Cancer Organisation (IKNL)
Royal Dutch Medical Association (KNMG)
National Association of General Practitioners (LHV)
Dutch College of General Practitioners (NHG)
Netherlands Federation of University Medical Centres (NFU)
Netherlands Patient Federation (PFNL)
Netherlands Association of Physicians for the Intellectually Disabled (NVAVG)
Netherlands Association for Psychosocial Oncology (NVPO)
Dutch Hospital Association (NVZ)
Dutch Society of Professionals in Palliative Care (Palliactief)
Quality of Care Council – Dutch Federation of Medical Specialists (RK-FMS)
Dutch Federation of Oncological Societies (SONCOS)
Netherlands Association for Nurses and Carers (V&VN)
Dutch Association of Elderly Care Physicians (Verenso)
Dutch Association of Spiritual Caregivers (VGVZ)
Netherlands umbrella organisation of health insurers (ZN)

SOUNDING BOARD
Centre for Social and Spiritual Support in Palliative Care (Agora)
Netherlands Association for Hospice Care (AHzN)
Palliative Care Expertise Centres (EPZ)
Royal Dutch Society for Physical Therapy (KNGF)
Dutch Cancer Society (KWF)
Netherlands Institute for Health Services Research (NIVEL)
National Programme for Palliative Care (NPPZ)
Cooperation of General Hospitals (SAZ)

SOUNDING BOARD (continued)
Dutch Platform for Palliative Care Networks (Stichting Fibula)
PAL Foundation for Pediatric Expertise in Palliative Care (Stichting PAL)
Cooperation of Top-Clinical Care Hospitals (STZ)
Volunteers for Palliative Care at the End of Life (VPTZ)
Ministry of Health, Welfare and Sport (Ministerie van VWS)
National Health Care Institute (ZiN)
Netherlands Organisation for Health Research and Development (ZonMw)

EXPERT PANEL
Dutch Federation of Medical Specialists (FMS)
Dutch College of General Practitioners (NHG)
Netherlands Patient Federation (PFNL)
Netherlands Association for Psychosocial Oncology (NVPO)
Netherlands Association for Nurses and Carers (V&VN)
Dutch Association of Elderly Care Physicians (Verenso)
Dutch Association of Spiritual Caregivers (VGVZ)
Netherlands umbrella organisation of health insurers (ZN)

OTHER INTERESTED PARTIES IN THE ROUND-TABLE DISCUSSIONS
Health and Youth Care Inspectorate (IGJ)
Dutch Cancer Society (KWF)
Dutch Federation of Cancer Patient Organisations (NFK)
Dutch Association for Anaesthesiology (NVA)
Dutch Association for Paediatric Medicine (NVK)
Standard for Palliative Care 1.0 Development Group
Project Group for Quality Indicators
Project Group for Palliative Care in District Nursing

S2 Delphi Survey for End-of-Life Care domain in Netherlands Quality Framework for Palliative Care

In this document* please find:

1. An overview of the core documents selected for construction of the Netherlands Quality Framework for Palliative Care (NQFPC)
2. A glossary of relevant terms.
3. A table containing all standards related to the End-of-Life Care domain from the various core documents accompanied by a clarification of the procedure to select relevant and suitable standards for the NQFPC.
4. Tables containing all criteria related to the End-of-Life Care domain from the various core documents accompanied by a clarification of the procedure to select relevant and suitable criteria for the NQFPC.
5. Reply sheet

*Similar documents for other domains of the NQFPC are available on request.

1. Core documents

Below you find an overview of the documents selected as core documents for constructing the NQFPC. These documents resulted from a literature search performed by the project team of peers and endorsed by the working group (see figure 2 in manuscript). Below the full name of the documents you will find the abbreviation used for identification by the project team in the Delphi procedure.

- Standards for providing quality palliative care for all Australians, PCA (2005)
  (AU)
- Hospice New Zealand standards for palliative care, Hospice NZ (2012)
  (NZ)
- Clinical practice guidelines for quality palliative care, NCP (2013)
  (NCP)
- Quality standard end-of-life care for adults, NICE (2013)
  (NICE)
- Standard for Palliative Care 1.0, CBO (2013)
  (ZM)
- Prezo Audit for Hospicecare, Perspekt (2015)
  (PREZO)

2. Glossary of relevant terms

The NQFPC consists of several domains that together cover all aspects of palliative care.

Domain: a demarcated area that describes a specific dimension of palliative care.

Standard: indicates best practice within a domain, taking into account recent findings and evidence.

Criterion: a condition which a specific aspect of care must meet to obtain the desired standard.

End-of-life care: care in the last days (up to 7 days) of life.

3. Standards

Clarification of procedure

On the next page the standards related to the End-of-life care domain in the various core documents are displayed in a table. The project team made an effort to group comparable standards as much as possible and aligned them horizontally. The column on the far right contains the standards proposed by the project team as suitable for the NQFPC.

N.B.

The Standard for Palliative Care 1.0, CBO (2013) describes criteria and no standards. Therefore, there is no column referring to the Standard for Palliative Care in this table.

Request to the working group

On the reply sheet at the end of this document members of the working group are kindly requested to indicate whether they can agree with the proposed standards or which other standards they would consider better suitable for the NQFPC. The numbers of the standards in the table below correspond to the numbers referred to on the reply sheet.

Table of standards relevant to the End-of-Life Care domain

AU(2005)	NZ(2012)	NCP (2013)	NICE (2013)	Prezo (2015)	Proposed standard for NQFPC
The unique needs of dying patients are considered, their comfort maximised and their dignity preserved. (AU_6)	The unique needs of patients in the last days of life, and the family and whanau, are considered, their comfort maximised and their dignity preserved. (NZ_8)	The interdisciplinary team (IDT) identifies, communicates, and manages the signs and symptoms of patients at the end of life to meet the physical, psychosocial, spiritual, social, and cultural needs of patients and families. (NCP_7.1)	People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication. (NICE_Statement 11)	De patiënt ervaart aandacht, comfort en ondersteunende zorg bij het afronden van het leven. (PREZO_Domein 6)	People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication. (NICE_Statement 11)
		The IDT assesses and, in collaboration with the patient and family, develops, documents, and implements a care plan to address preventative and immediate treatment of actual or potential symptoms, patient and family preferences for site of care, attendance of family and/or community members at the bedside, and desire for other treatments and procedures. (NCP_7.2)			The IDT assesses and, in collaboration with the patient and family, develops, documents, and implements a care plan to address preventative and immediate treatment of actual or potential symptoms, patient and family preferences for site of care, attendance of family and/or community members at the bedside, and desire for other treatments and procedures. .(NCP_7.2)
		Respectful postdeath care is delivered in a respectful manner that honors the patient and family culture and religious practices. (NCP_7.3)	The body of a person who has died is cared for in a culturally sensitive and dignified manner. (NICE_Statement 12)		Respectful postdeath care is delivered in a respectful manner that honors the patient and family culture and religious practices. (NCP_7.3)
			Families and carers of people who have died receive timely verification and certification of the death. (NICE_Statement 13)		
		An immediate bereavement plan is activated postdeath. (NCP_7.4	People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences. (NICE_Statement 14		An immediate bereavement plan is activated postdeath. (NCP_7.4)

4. Criteria

Clarification of procedure

On the next pages all criteria related to the standards of the End-of-life care domain in the various core documents are displayed in several tables. To facilitate the working group, the project team made an effort to group criteria as much as possible referring to specific phases in End-of-life care. The tables have the following subjects regarding end-of-life care:

- General
- Pre-death
- Peri-death
- Post-death
- Other

N.B.
NICE (2011) describes standards (statements) without additional criteria. It does describe accessory indicators, however these do not fit the scope of the NQFPC. Therefore, there is no column referring to NICE (2011) in the following tables.

Request to the working group

On the reply sheet at the end of this document members of the working group are kindly requested to indicate for each criterion whether it should be incorporated in the NQFPC. Each criterion carries a unique combination of letters and numbers. These combination – codes can be found in the far-left column on the reply sheet.

Table of general criteria relevant to End-of-Life Care domain

Criteria AU (2005)	NZ(2012)	Criteria NCP (2013)	Criteria Zorgmodule (2013)	Criteria Prezo (2015)
Guidance and support is given to primary care providers regarding decision making and end-of-life care (AU_6.9)	-	Care of the patient at the end of life is time and detail intensive, requiring expert clinical, social, and spiritual attention to the process as it evolves. Care of the patient is divided into three phases; pre death, peri death, and post death. (NCP_7.1.1)	-	De patiënt of zijn naaste geeft aan en/of heeft aangegeven wat hij comfortabel vindt om zijn lichamelijke, psychische, sociale en spirituele klachten en symptomen zoveel mogelijk te verminderen. (PREZO_domein6.1p)
Protocols to guide care at the end of life are developed and disseminated (AU_6.10)				de medewerker zorgt voor zoveel mogelijk comfort voor de patiënt (PREZO_domein6.1m)
Processes are established to respond to the need for urgent assessment and guidance (AU_6.11)				de medewerker bespreekt verlies- en rouwgevoelens met de patient en/ of naasten als zij hiervoor open staan (PREZO_domein6.3m)
Guidance and support is available to health care providers seeking advice about ethical dilemmas related to end-of-life care and decision-making. (AU_6.12)				de medewerker heeft aandacht voor emoties bij de patient en/of naaste (PREZO_domein6.4m)
				De medewerker stelt de draagkracht en draaglast van de patient en zijn naasten vast, signaleert mogelijke overbelasting en handelt hiernaar (PREZO_domein6.7m)
				De medewerker legt de gemaakte afspraken in het individueel zorgplan vast, evalueert deze met de patient en stelt zo nodig de afspraken bij (PREZO_domein6.8m)

Table of criteria relevant to pre-death phase in End-of-Life Care domain

Criteria AU (2005)	Criteria NZ (2012)	Criteria NCP (2013)	Criteria Zorgmodule (2013)	Criteria Prezo (2015)
Regular and ongoing assessment of the patient identifies transition into the terminal phase. (AU_6.1)	the concerns, hopes, fears and expectations of the imminently dying patient and their family and whanau are discussed openly and honestly in a way that is appropriate for their age, culture, spiritual and social situation. (NZ_8.1)	With the patient and family, a plan is developed to meet their unique needs during the dying process as well as the needs of family immediately following the patient's death. Reassessment and revision of the plan occurs in a timely basis. (NCP_7.2.2)	Monitor het stervensproces en pas de zorg daarop aan (ZM_stervensfase_4.1)	De patiënt of zijn naaste geeft aan en/of heeft aangegeven wat voor hem belangrijk is bij de afronding van het leven zoals: -aandacht voor de betekenis die hij geeft aan kwaliteit van leven en sterven -het leven voltooien in waardigheid en eigenheid -emotionele steun -begeleiding bij beslissingen rondom het levenseinde -aandacht voor waarden en keuzen -wensen en behoeften op lichamelijk, psychisch, sociaal en spiritueel gebied -uitvoeren van rituelen -steun bij het nemen van afscheid en loslaten van het leven -betrokkenheid en ondersteuning van naasten bij en na het overlijden (PREZO_domein6.2p)
End of life issues and anticipation of death are honestly discussed with the patient, their caregiver/s and family in a socially and culturally appropriate manner. (AU_6.2)	the family is educated regarding the signs and symptoms of approaching death, in a way that is appropriate for their age, culture and social situation. (NZ_8.3)	In collaboration with the patient and family, the IDT provides care with respect for patient and family values, preferences, beliefs, culture, and religion. (NCP_7.1.4)	Stel vast wie nazorg geeft en dient te ontvangen (ZM_stervensfase_5.2)	Patiënt of zijn naaste bepaalt en/of heeft aangegeven welke activiteiten in zijn stervensfase: -hij zelf wil uitvoeren -door zijn naasten uitgevoerd worden -door vrijwilligers/medewerkers/organisatie uitgevoerd kunnen worden. (PREZO_domein6.3p)
Symptoms at the end of life are assessed and documented with appropriate frequency and treatment and care is based on patient, their caregiver/s and family needs and wishes. (AU_6.3)	information and discussion on after death wishes and decisions is facilitated, if wanted (NZ_8.4)	Before the patient's death, sensitive communication occurs, as appropriate, about autopsy, organ and tissue donation, and anatomical gifts, adhering to institutional and regional policies. (NCP_7.2.5)		de medewerker inventariseert met de patiënt en/of zijn naasten wensen en behoeften t.a.v. het stervensproces en de praktische zaken vlak voor en na het overlijden en zet zich in om deze te realiseren (PREZO_domein6.2m)

Table of criteria relevant to pre-death phase in End-of-Life Care domain (continued)

The caregiver/s and family members are given information regarding the signs and symptoms of approaching death in a manner appropriate to their individual needs and circumstances. (AU_6.4) signs and symptoms of approaching death in a manner appropriate to their individual needs and circumstances. (AU_6.4)		Any inability to honor the patient's and family's expressed wishes for care immediately leading up to and following the patient's death is documented and communicated in the medical record that is accessible to other health care providers. (NCP_7.2.3)		de medeweker signaleert, inventariseert en beoordeelt, zo mogelijk met behulp van instrumenten, de aard en ernst van de klachten, risico's en/of symptomen die de patient ervaart (fysiek: pijn, benauwdheid, misselijkheid/braken; emotioneel: angst, depressiviteit, boosheid, ontremming; cognitief: moeite met denken, begrijpen, onthouden, plannen & organiseren, besef van tijd, plaats of persoon). Bespreekt dit met patient en/of naasten en neemt in overleg passende en preventieve maatregelen (PREZO_domein6.5m)
		For patients who have not accessed hospice services, care planning at this stage may include the introduction or reintroduction of hospice referral, if such an option is congruent with the patient's and family's goals and preferences. (NCP_7.2.4)		De medewerker signaleert en inventariseert samen met de patient (pro)actief: -situaties waarin volstaat kan worden met alledaagse aandacht voor het afronden van het leven -situaties waarin de patient behoefte heeft aan begeleiding bij het afronden van het leven en situaties waarbij begeleiding door een deskundige toegevoegde waarde kan hebben -situaties waarin een crisis ontstaat die vraagt om een crisisinterventie door een expert (PREZO_domein6.9m)

Table of criteria relevant to peri-death phase in End-of-Life Care domain

Criteria AU (2005)	Criteria NZ (2012)	Criteria NCP (2013)	Criteria Zorgmodule (2013)	Criteria Prezo (2015)
Provision is made to enable the patient and family to participate in customary or religious end of life rituals that have meaning for them. (AU_6.5)	When the patient is assessed as imminently dying the care plan is revised to reflect the needs of the patient and family and a last days of life care pathway is implemented. (NZ_8.2)	The IDT assesses the patient for symptoms and proactively prepares family and other caregivers on the recognition and management of potential symptoms and concerns. (NCP_7.2.1)	Vaststellen van het stervensproces en monitoren van het zorgplan (ZM_stervensfase_3.1) Besteed aandacht aan afscheid en rouw bij patiënt en naasten (ZM_stervensfase_ 1.4)	de medewerker gaat in de stervensfase na: -wat de patient zelf wil doen -wat de naasten van de patient doen -wat de vrijwilligers/medewerkers/ organisatie doen (PREZO_domein6.6m)
Plans are in place for the certification of death should this occur out of hours. (AU_6.7)	There are processes in place to respond to the need for urgent assessment and guidance for all providers caring for patients in the last days of life . (NZ_8.6)		Vraag de stervende naar storende symptomen (ZM_ stervensfase_ 1.2) Let op signalen die wijzen op (naderend) sterven (ZM_stervensfase_ 2.1) Let op symptomen en pas het onderzoek aan (ZM_stervensfase_ 2.2) Vraag naasten naar opvallende signalen en symptomen en exploreer deze (ZM_stervensfase_ 1.3)	
	Guidance and support is available to health care providers seeking advice about ethical dilemmas related to last days of life care and decision making. (NZ_8.7)		Zorg is gericht op comfort (ZM_stervensfase_ 1.1)	

Table of criteria relevant to post-death phase in End-of-Life Care domain

Criteria AU (2005)	Criteria NZ (2012)	Criteria NCP (2013)	Criteria Zorgmodule (2013)	Criteria Prezo (2015)
Immediately following the death of the patient and during the early bereavement phase, caregiver/s and families are given time and continuing care to provide comfort, and assist with adjustment to the death of the patient. (AU_6.6)	-	In post death, the focus of care includes respectful care of the body and support of the family. (NCP_7.3.1)	Geef ruimte voor rituelen (ZM_stervensfase_ 4.3)	-
All providers of care (in particular the patient's general practitioner) receive information about the end phase of illness and/or death as soon as possible. Personal communication via telephone precedes official written communication. (AU_6.8)		The IDT assesses and documents cultural and religious practices particular to the post death period, and delivers care honoring those practices, in accordance with both institutional practice, local laws, and state regulations next to domain 5: spiritual, religious, and existential aspects of care and domain 6: cultural aspects of care. (NCP_7.3.2)	Realiseren van praktische afspraken (wie verwittigen) (ZM_stervensfase_ 5.1)	
		As described in domain 3: psychological and psychiatric aspect of care the IDT formulates and activates a post death bereavement plan based on a social, cultural, and spiritual grief assessment. (NCP_7.4.1)		
		A health care team member is assigned to support the family in the post death period and assist with religious practices, funeral arrangements, and burial planning. (NCP_7.4.2)		

Table of other criteria relevant to End-of-Life Care domain

Criteria AU (2005)	Criteria NZ (2012)	Criteria NCP (2013)	Criteria Zorgmodule (2013)	Criteria Prezo (2015)
	Plans are in place for the certification of death, including plans for certification after hours. (NZ_8.5)	The IDT recognizes the need for high acuity and high intensity care during the dying process. (NCP_7.1.2)	Geef adviezen over houding en (stoppen met) voeding (ZM_stervensfase_ 4.2)	
	Support all providers of palliative care to adopt and implement a last days of life care pathway. (NZ_8.8)	The IDT routinely elicits and honestly addresses concerns, hopes, fears, and expectations about the dying process in a developmentally appropriate manner, with respect for the social and cultural context of the family next to domain 6: cultural aspects of care. (NCP_7.1.3)		
		The IDT acknowledge the patient's needs at the end of life and educate the family and other care providers about what to expect in terms of death. As death approaches, they communicate signs and symptoms of imminent death, in culturally and developmentally appropriate language, with attention to population specific issues and age appropriateness. (NCP_7.1.5)		

References

- Palliative Care Australia. Standards for providing Quality Palliative Care for all Australians, 2005.
- National Institute for Health and Care Excellence. Quality standard for end-of-life care for adults, 2011.
- Hospice New Zealand. Hospice New Zealand Standards for Palliative Care. Wellington, 2012.
- National Consensus Project for Quality Palliative Care. Clinical practice guidelines for quality palliative care. Pittsburgh: National Consensus Project for Quality Palliative Care, 2013.
- CBO. Zorgmodule Palliatieve Zorg 1.0, 2013.
- Stichting Perspekt. Prezo Hospicezorg. Utrecht, 2015.

Replysheet
Domain: End-of-Life Care
Name working group member: _

Standards

Members of the working group are kindly requested to indicate whether they can agree with the proposed standards or which other standards they would consider better suitable for the NQFPC. The numbers of the standards mentioned in the reply table below correspond to the numbers indicated after each proposed standard in the “table of standards relevant to the End-of-life care domain”.

In the table below please indicate for each proposed standard:

- whether you can agree and
- If, and how, you would want to adapt or extend the text of the proposed standard; or
- whether you disagree (please add argumentation)

When you prefer to add another standard from the table or you find there is a standard missing for this specific domain, please indicate this in the bottom table.

Number of standard	Agree, (with potential suggestion for adaptation / extension)	Disagree (please add argumentation)
NICE_Statement 11		
NCP_7.2		
NCP_7.3		
NCP_7.4		

Suggestions for additional standards for this specific domain:

Criteria
Members of the working group are kindly requested to indicate for each criterion mentioned in the five separate tables above whether it should be incorporated in the NQFPC. Each criterion carries a unique combination of letters and numbers. The numbers of the criteria mentioned in the reply table below correspond to these combination – codes indicated after each criterion in the five tables above.

In the table below please indicate for each criterion:
- whether the criterion should be incorporated and
- If, and how, you would want to adapt or extend the text of the criterion; or
- whether the criterion should not be incorporated (please add argumentation)

When you find there is a criterion missing for this specific domain, please indicate this in the bottom table.

Examples of reasons not to incorporate a criterion are:
- the criterion is not suitable or appropriate for this specific domain
- the criterion is more suitable for the primary domain "Core values and principles".
- the criterion is similar to another criterion that you already indicated to incorporate.
- the content of the criterion is not suitable for the Dutch healthcare setting

The selected and newly suggested standards and criteria will be presented and discussed in the next working group meeting. After agreement on incorporation, the domain will be constructed for presentation to Steering group, Sounding board group and consultation of peers.

Number of criterion	Yes, incorporate in this domain, (with potential suggestion for adaptation / extension)	No, do not incorporate (please add argumentation)
General		
AU_6.9		
AU_6.10		
AU_6.11		
AU_6.12		
NCP_7.1.1		
PREZO_domein6.1p		
PREZO_domein6.1m		
PREZO_domein6.3m		
PREZO_domein6.4m		

PREZO_domein6.7m		
PREZO_domein6.8m		
Pre-death		
AU_6.1		
AU_6.2		
AU_6.3		
AU_6.4		
NZ_8.1		
NZ_8.3		
NZ_8.4		
NCP_7.2.2		
NCP_7.1.4		
NCP_7.2.5		
NCP_7.2.3		
NCP_7.2.4		
ZM_stervensfase_4.1		
ZM_stervensfase_5.2		
PREZO_domein6.2p		
PREZO_domein6.3p		
PREZO_domein6.2m		
PREZO_domein6.5m		
PREZO_domein6.9m		
Peri-death		
AU_6.5		
AU_6.7		
NZ_8.2		
NZ_8.6		
NZ_8.7		
NCP_7.2.1		
ZM_stervensfase_3.1		
ZM_stervensfase_1.4		

ZM_stervensfase_1.2		
ZM_stervensfase_2.1		
ZM_stervensfase_2.2		
ZM_stervensfase_1.3		
ZM_stervensfase_1.1		
PREZO_domein6.6m		
Post-death		
AU_6.6		
AU_6.8		
NCP_7.3.1		
NCP_7.3.2		
NCP_7.4.1		
NCP_7.4.2		
ZM_stervensfase_ 4.3		
ZM_stervensfase_ 5.1		
overige		
NZ_8.5		
NZ_8.8		
NCP_7.1.2		
NCP_7.1.3		
NCP_7.1.5		
ZM_stervensfase_ 4.2		

Suggestions for additional standards for this specific domain:

S3 Results from the bottleneck analysis of palliative care provision in the Netherlands

Bottlenecks / Barriers		Literature Inventory (2005 – 2015)	Hospital Survey	Invitational ConferencePrimary Care
Information & Communication	Patients	• Flawed information (treatment options, pro's & con's, expected results); • Written information is scarce; • Unclear communication about prognosis, often (just) shortly before dying; • Insufficient involvement in decision making.		
	Healthcare professionals			• Insufficient engagement with patients about death and dying and advance care planning.
Coordination & Continuity of Care	Patients	• Inadequate coordination between healthcare professionals; • Inadequate transfer information between hospital and primary care; • Difficulty getting a second opinion; • Difficulty in reaching healthcare organisations; • Irregular visits of community-based nurses; • Many different healthcare professionals per patient; • Difficulties in handling acute problems (fear for sudden hospital admission).		
	Healthcare professionals	• Difficult cooperation with community-based nurses (too many community care organisations); • Inadequate information transfer between hospital and primary care; • Inadequate or insufficient information transfer to out-of-hours physician services; • No clear agreement on 'leading healthcare professional' • Inadequate coordination between hospital and primary care;	• No clear assignment of the board for specialist palliative care. • Lack of continuity of care through lack of staff.	• Insufficient coordination of care with primary care physician while patient is treated by medical specialist; • Inadequate information transfer between hospital and primary care; • Discontinuity of care out-of-hours; • Inadequate or insufficient information transfer to out-of-hours physician services; • Inadequate information transfer between primary care physicians and community based nurses;

S3 Results from the bottleneck analysis of palliative care provision in the Netherlands (continued)

Coordination & Continuity of Care (continued)	Healthcare professionals	• Insufficient continuity of care from healthcare professionals; • Higher frequency in transfer of care due to increase in part time working healthcare professionals.		• Primary care physician has no access to digital information system of community care organisations; • No clear agreement on ‘leading healthcare professional’; • Through insufficient information transfers, healthcare professionals cannot provide appropriate care to their patients and patients have to frequently repeat their needs or wishes.
Expertise, training & education	Patients	• Insufficient spiritual care; • Insufficient psychosocial support (anxiety, depression); • Inadequate support of physical symptoms (dyspnea, pain, constipation); • Lack of education and training (especially among primary care physicians).		
	Healthcare professionals	• Healthcare professionals have a different understanding of the concept of palliative care; • No acknowledgement of the palliative care trajectory; • No anticipating the palliative care trajectory; • Difficulty in discussing end of life; • Lack of advance care planning; • Insufficient attention for psychological support; • Insufficient attention for spiritual needs; • Insufficient knowledge about death and dying in other cultures; • Insufficient attention for informal caregiver(s); • Family physicians have insufficient knowledge of locally or regionally provided care; • Focus on treatment of the disease.	• Unconscious incompetence among colleagues; • Unfamiliarity with palliative care; • Reluctance in identifying palliative care trajectory; • Unaware of added value of specialist palliative care • There is no room for palliative care in disease-modifying treatment	• Lack of knowledge and competence with regard to palliative care; • Insufficient advance care planning.

S3 Results from the bottleneck analysis of palliative care provision in the Netherlands (continued)

Rules, Regulations & Reimbursement	Healthcare professionals	• Bureaucracy to obtain palliative care indication; • High administration load.	• Ambiguity on reimbursement and available finances; • Lack of dedicated time / hours.	• Palliative care is intensive care with regard to patient care as well as coordination of care with other healthcare professionals. Reimbursement for providing appropriate palliative care is insufficient, fragmented and complex to obtain; • Some reimbursements require a statement of limited life expectancy. Aside from the extra administration load, this does not align with the current view that palliative care is best integrated early, i.e., the last year of life. • The goal of efficiency in the current healthcare system does not align with the amount of time required to provide appropriate care for patients and their families and to coordinate care with other healthcare professionals.

References

IKNL/Palliactief. Knelpuntenanalyse Palliatieve Zorg in de eerste lijn (Bottleneck analysis of primary palliative care). Utrecht, 2017.

IKNL/Palliactief. Palliatieve Zorg in Nederlandse ziekenhuizen (Palliative care in Dutch hospitals). Utrecht, 2015.

Brinkman-Stoppelenburg A, Boddaert M, Douma J, et al. Palliative care in Dutch hospitals: a rapid increase in the number of expert teams, a limited number of referrals. *BMC Health Serv Res.* 2016;16(1):518.

Chapter 7

General Discussion

This thesis presents the results of studies that aimed to gain a better understanding of the value, availability and accessibility of palliative care in a mixed generalist specialist palliative care model. In addition, it provides insight into the process of developing a national quality framework for palliative care and presents the key elements of quality palliative care for integration with regular care. This chapter highlights the main findings and discusses relevant methodological issues. Subsequently, implications of our results are viewed in a broader perspective and recommendations for clinical practice, education, policy and research are presented.

Main findings

Practice of hospital-based specialist palliative care teams and their characteristics

In 2015, our survey on palliative care among all Dutch hospitals showed that the number of hospitals providing a specialist palliative care team with inpatient consultation services had increased steadily from 39% in 2013 to 77% in 2015. However, their involvement in the provision of palliative care for patients with a serious life-threatening or life-limiting illness was low, as the mean referral rate of these specialist palliative care teams was only 0.6% of all annual hospital admissions. In addition to the observed substantial differences between the teams in terms of the number and timing of referrals, there was a great diversity regarding the disciplines represented on these teams, as well as their level of staffing and expertise and their working procedures.

Team-development over time and characteristics associated with high referral rate

In 2018, the abovementioned national survey among all Dutch hospitals was repeated. While the number of hospitals providing a specialist palliative care team had increased to 94%, the mean referral rate to these teams remained low, showing only a marginal increase to 0.85%. Moreover, for the majority of teams (55%) referrals still mostly only occurred for patients in their last month of life and the proportion of non-oncology referrals was small. In addition, we observed that higher referral rates (>1% of total annual hospital admissions) seem to be associated with teams being more mature, better staffed and better trained, and having access to patients at an earlier moment in their disease trajectory. The latter may be linked to dedicated outreaching programmes of these specialist palliative care teams as they more often provide outpatient palliative care clinics, participate in multidisciplinary team meetings of other departments and provide education in the community.

Association between palliative care and potentially inappropriate end-of-life care

To assess the association between palliative care prior to the last month of life and health care utilisation in the last month of life, we retrospectively compared quality indicators for potentially inappropriate end-of-life care of patients with cancer who did not receive palliative care at all or not until their last month of life to patients who were provided with palliative care before their last month of life.

In a nationwide study, data collected from a national administrative health insurance database for patients with cancer who died in 2017 demonstrated that more than one third of patients experienced potentially inappropriate care in the last month of their life. Patients who received palliative care prior to the last month of their lives (39%) were five times less likely to experience potentially inappropriate care in the last month of their life than patients who did not (16% vs 45%, adjusted OR 0.2). In most cases, palliative care consisted of generalist palliative care (88%).

In view of complex reimbursement regulations for hospital-based specialist palliative care teams in 2017 most likely this type of care was under registered in the national administrative health insurance database.

In a subsequent study we therefore applied a similar study-design to administrative hospital data of two acute care hospitals and showed that more than one fourth of patients with cancer who died in 2018 or 2019 experienced potentially inappropriate care in the last month of their life. Patients with involvement of the specialist palliative care team (13%) before their last month of life were nearly two times less likely to experience potentially inappropriate care in the last month of their life than patients without involvement of the specialist palliative care team or no involvement until their last month of life (19% vs 28%, adjusted OR 0.55). Initiation of specialist palliative care in the outpatient setting seemed to strengthen this association.

Development of a national quality framework for palliative care

The overall results of these four studies substantiate the necessity to improve availability and realise equitable access to palliative care, attuned to the individual complexity of patients' needs. As such, our findings support the development of a national quality framework for palliative care to improve the organisation and delivery of patient-centred palliative care.

By inviting patients, healthcare professionals from various disciplines, health insurers, and policymakers to participate, all stakeholders pooled their aspirations, information, resources, knowledge and skills to successfully reach consensus for a 'Netherlands Quality Framework for Palliative Care' (NQFPC) that none of the parties involved could have achieved independently. This whole-sector approach succeeded in obtaining broad consent and recognition for provision of high-quality, person-centred palliative care in a mixed generalist specialist model that can be integrated across all care settings. To primarily address the barriers to quality palliative care provision that were identified in the bottleneck analysis, eight elements from the NQFPC were prioritised as key elements for the integration of palliative care with regular health care (Table 1).

Table 1. Key elements of NQFPC prioritised for integration of palliative care with regular care.

Key elements of palliative care	
Effective Communication	**Individual Care Plan**
Identification	**Coordination & Continuity of Care**
Shared Decision Making	**Work-Life Balance**
Advance Care Planning	**Expertise** (education & training)

*A key element consists of a specific standard and their affiliated criteria as described in the NQFPC.[1]

Methodological considerations

In the observational studies presented in this thesis, different research methodologies and methods of data collection were used. Chapters 2 and 3 describe findings collected through an online survey, chapters 4 and 5 present data extracted from health care administrative databases and chapter 6 describes a modified Delphi technique.

Online surveys

The online survey methodology facilitated the nationwide purpose of these consecutive studies. For a high response rate, recruitment consisted of a personal invitation to each hospital-based specialist palliative care team and participation was rewarded with a factsheet of their own data in relation to the overall results. This resulted in a consistently high response rate of 80%. This high response rate, together with information obtained from non-respondents indicating they had similar characteristics to the respondents, makes selection bias unlikely and the findings generalisable to all Dutch hospitals.

In analysing the collected data, referral rate was used to express the reach of specialist palliative care teams as a percentage of total annual hospital admissions. Although referral rate is a regularly used measure of accessibility and availability of specialist palliative care, and chapters 4 and 5 showed access to palliative care to be associated with less potentially inappropriate end-of-life care, it does not provide insight into the quality level of palliative care provided by specialist palliative care teams.

Another limitation of the online survey studies is that requested data are self-reported. Not all data were necessarily quantified at the patient-level as specialist palliative care teams structurally register most, but not all information that was requested in the surveys. This may have led to recall and reporting bias and for instance, to potential enhancement of data. However, while the availability of teams has increased over the years, the results to date show a continuously limited accessibility or involvement of these teams in the care for seriously ill patients in comparison to international studies. Moreover, the hypothesis that hospital palliative care programmes with high referral rates would be better staffed and better integrated and would have earlier timing of referrals was initially based on international literature and subsequently confirmed in our last survey.[2-4] So, while enhancement of data appears unlikely, even if it did occur, the trends in growth and development that we observed can still provide valuable information, and they are consistent with results from other studies.

Health care administrative data

For the population-based assessment of potentially inappropriate end-of-life care and its association with palliative care provision, health care administrative data were gathered from a national health insurance database and from two electronic patient management healthcare information exchange (HIX) databases respectively. As administrative data are not primarily collected for the purpose of research or quality assessment, it is important to carefully code the quality indicators to render them measurable, and to check the coding and the concept query repeatedly with medical and reimbursement experts who are familiar with the database to establish veracity, i.e., misclassification is prevented as much as possible and collected data will be of sufficient quality and accuracy to generate actionable information.[5 6] To determine our research population we used ICD 10 diagnoses and diagnosis related groups (DRGs).[7] In several studies, ICD diagnoses for colorectal, lung, breast and bile duct cancer were abstracted from the medical records and used as the “gold standard”, against which diagnoses obtained for the same patients from the administrative database were compared. The administrative data were found to be highly specific and sensitive.[8-12] With regard to our collected data on health care utilisation, a study compared data for length of stay and discharge destination between inpatient medical records and administrative data from an electronic patient management programme. Results indicated that the highest level of completeness of capture and level of agreement can be obtained.[13] Important strengths of this type of research are that, unlike studies using sample data, the use of administrative data precludes sampling, nonresponse, and recall bias.[14] Moreover, studying end-of life care in vulnerable populations is otherwise ethically and methodologically challenging.[5] Health care administrative data can therefore be considered an acceptable data collection source for population-based research using ICD diagnostic codes and validated population-based quality indicators for inappropriate end-of-life care.[8-13 15]

However, as administrative data are observational data that lack clinical information about complexity of needs and content of care provided, confounding by indication might occur, e.g. patients may or may not receive palliative care for a reason that might also be related to the outcome. Therefore, we cannot infer causality, only association.[16]

Modified Delphi technique

For the development of the national quality framework, we adhered to the Guideline for Guidelines[17], a complementary tool to the revised international criteria for Appraisal for Guidelines of Research and Evaluation (AGREE II)[18]. To answer the research question, we used a modified Delphi technique in the sense that we alternated between written Delphi survey rounds and face-to-face meetings of the expert panel.[19] Although it has been a longstanding custom in the development of medical guidelines in the Netherlands to build consensus in face-to-face meetings, it may be argued that live discussions and personal interaction will unavoidably evoke bias.[19] Therefore, to limit the level of bias, each face-to-face meeting with members of the expert panel was followed by a Delphi survey round amongst them. To ensure full impartiality, drafts of the quality framework were submitted for written peer consultation rounds and the final draft was submitted for ultimate review and authorisation at board management level of organisations represented in the expert panel.

Results in a broader perspective

The demography of ageing and an exponential growth of curative and rehabilitative treatment strategies have resulted in older populations with more complex care needs.[20] Non-communicable chronic diseases (including cancer, dementia, obstructive lung disease, heart disease and neuro-degenerative diseases) are currently the leading cause of morbidity and mortality in high income countries,[21] where approximately 75% of people die from life-threatening and life-limiting illnesses, with evolving and increasing health care needs.[22] Meeting these care needs places ever greater demands on society and healthcare systems.[23] Since 2011, the General Assembly of the United Nations advocates a whole-of-government and a whole-of-society approach for the national prevention and control of non-communicable diseases.[24] Therefore, in the following paragraphs the main findings of this thesis are discussed in relation to its aims, current literature and ongoing efforts of government and society to improve palliative care in the Netherlands. This will iteratively result in recommendations for clinical practice, education, policy and research.

Value of palliative care in a mixed generalist specialist palliative care model

Multiple international randomised and matched-controlled trials have demonstrated that the integration of either specialist or generalist palliative care into standard oncology or non-oncology care improves the quality of life and quality of end-of-life care for patients with advanced cancer and other life-limiting diseases.[25-31] As a result, international professional organisations recommend earlier and routine co-management by palliative care specialists.[32-34] Our main findings show that **timely provision of generalist and specialist palliative care is associated with significantly less potentially inappropriate end-of-life care for patients with advanced cancer in the Netherlands**.[35 36] Additionally, **outpatient initiation of specialist palliative care appears to strengthen this association.** Several international observational studies have demonstrated similar associations between palliative care and healthcare utilisation at the end of life for patients with cancer as well as non-cancer diseases and frailty.[37-42] As less potentially inappropriate end-of-life care is associated with better patient quality of life,[43 44] and also with better caregiver quality of life and bereavement adjustment,[45 46] results in this thesis support the importance of timely availability and equitable accessibility of palliative care for all patients with serious life-threatening disease or frailty.

Availability of palliative care

Results from our healthcare administrative data studies demonstrated the majority of patients with cancer either received no generalist or specialist palliative care at all or not until the last few weeks or days of their life.[35 36] Additionally, although specialist palliative care teams were found to be available in nearly all hospitals,[47] referrals to these teams were continually shown to be low and most often do not occur until the last weeks of life.[36 47 48]

These results are in line with a recent one-day flash mob study in the Netherlands regarding 8,789 hospitalised patients in 48 hospitals. Involved healthcare professionals estimated 4.3% of these patients had a need for specialist palliative care and in just 2.2% the specialist palliative care team was involved.[49] Similarly, in a survey among 572 executives, clinical leaders, and clinicians directly involved in health care delivery and palliative care programmes across the United States (US) participants estimated that 60% of patients who could benefit from palliative care were not receiving it.[50] Suggestions for improvement focused mostly on staffing of palliative care specialists and additional training for palliative care generalists (both primary care physicians and medical specialists). Our findings implicate that palliative care services are not available to all patients with serious chronic illnesses as a matter of course.

The next paragraphs will consider some factors that may contribute to this **limited availability of palliative care** as well as ongoing efforts to improve it.

Impeding factors to availability of palliative care

- *Limited staffing of specialist palliative care teams:*

Our studies demonstrated a great diversity regarding the disciplines represented on the specialist palliative care teams, as well as their level of staffing and expertise and their working procedures.[47 48] On average, specialist palliative care teams in Dutch hospitals reached 0.85% of 23,622 annually admitted patients and they were staffed with 1 full time equivalent (FTE) nurse and 0.4 FTE physician.[47] In comparison, a similar study in the United States showed a referral rate of 3,4% for the lowest staffing quartile of 1.5 total FTE per 10,000 patients admitted.[2] Our study as well as others show that better staffing seems associated with higher referral rates and access to patients at an earlier moment in their disease trajectory.[2 3] However, staffing needs or required workforce-capacity of specialists in palliative care have not been calculated in the Netherlands, as they have been in Canada and Australia.[51-53]

- *Lack of training and education of palliative care generalists:*

In the bottleneck analysis performed prior to development of the NQFPC, both patients and healthcare professionals identified lack of communication skills and lack of palliative care education and training among healthcare professionals as barriers to quality palliative care provision.[54] This is in line with results from a systematic review of 37 studies, in which most healthcare professionals in hospitals perceived and provided generalist palliative care as care in the last weeks and days of life and professed a lack of sufficient training and skills in pain and symptom management, (end of life) communication, and care coordination.[55]

In the Netherlands general palliative care training is neither fully integrated nor required in undergraduate and graduate healthcare education.[56] A recent study gathering the views of 222 undergraduate final-year Dutch medical students on palliative care in terms of its importance, their confidence in and knowledge of the domain demonstrated that they considered palliative care education relevant and that several topics were inadequately covered in the curriculum. Overall, the majority of students (60%) did not feel confident in providing palliative care.[57]

As nursing staff have a prominent role in daily caregiving, they are conveniently positioned to discuss care wishes, to identify burdensome symptoms, and to increase quality of life.[58] However, Dutch nursing staff providing generalist palliative care for persons with dementia report difficulties in recognising and addressing pain and other physical, psychosocial, and spiritual care needs, dealing with challenging behaviors and communicating with patients.[59 60]

In two consecutive hospital-wide surveys in a Dutch academic hospital, generalists in palliative care consistently indicated needing support with basic palliative care skills.[61] Respondents' main concerns were that disease-directed treatment is often continued too long, underlying problems that patients have are frequently not acknowledged and patients who might benefit from palliative care are mostly identified too late. As generalists tend to overestimate survival and mostly do not refer patients until late in a palliative care trajectory, it was recommended for specialist palliative care teams to continuously focus on educating palliative care generalists and support them to identify, treat and refer patients with palliative care needs in a timely manner.[61]

A pervasive lack of training among current and future palliative care generalists has led to limited availability of generalist palliative care, low accessibility of specialist palliative care and thus to suboptimal quality palliative care in everyday practice.

- *Fragmented healthcare system and limited interdisciplinary teamwork:*

Patients in a palliative care trajectory often move between services and healthcare settings, have changing and often increasing needs for treatment and support, have multiple problems and symptoms and receive care from a variety of healthcare professionals.[62-65] Availability of integrated palliative care to support these patients requires mutual cooperation and coordination between palliative care generalists and specialists across care settings.[51] The bottleneck analysis performed prior to development of the NQFPC identified lack of interdisciplinary coordination and continuity of care as one of the barriers to quality palliative care provision.[54] A recent population-based study indicated that patients who received inpatient palliative care were more likely to experience continuity of community palliative care after discharge than those who received no inpatient palliative care.[66] This may well have been a contributing factor to the association between hospital-based specialist palliative care provision and less potentially inappropriate end-of-life care presented in this thesis. However, Dutch healthcare professionals indicate that the transition between hospital and primary care is hindered by a lack of identification of the palliative care trajectory and by uncertainties about the patients' and caregivers' awareness of prognosis. Interdisciplinary communication between healthcare professionals is needed but unfortunately lacking and uncertainties regarding physicians' responsibility for the patient seem to further hinder healthcare professionals in the coordination and continuity of care provision across care settings.[54 67 68]

Ongoing efforts to improve availability

- *Training and education of palliative care generalists:*

In an effort to improve availability of generalist palliative care, a Dutch randomised controlled trial among 134 family physicians evaluated the effect of a training to identify patients with palliative care needs and to subsequently provide structured anticipatory palliative care.[69] Assessing healthcare utilisation of all deceased patients with cancer, chronic obstructive pulmonary disease or chronic heart failure between trained and untrained family physicians, no significant difference was found. However, a post-hoc analysis showed patients identified with palliative care needs had had significantly more contact with their family physician, had undergone less hospitalisations, and more often died at home than the other deceased patients.[69] A follow-up of participating family physicians 1 year after either receiving or not receiving this training showed that trained physicians identified significantly more patients in a palliative care trajectory than untrained physicians and more often provided multidimensional and multidisciplinary palliative care.[70]

To address the lack of palliative care training and education among healthcare professionals, over past years the Netherlands Organisation for Health Research and Development (ZonMw) has funded the whole-sector development of an educational competency framework for palliative care across all levels of healthcare education (Improving Education in Palliative Care; O^{2}PZ).[71] This educational framework was based on the eight key elements of the NQFPC and carries broad recognition. However, as yet, integration of palliative care education in healthcare curricula at universities and in all levels of continued vocational education is not mandatory.

To improve generalist palliative care provision in oncology KWF Dutch Cancer Society recently funded the launch of a national palliative care training programme for healthcare professionals in oncology.

- *Integration of specialist palliative care services:*

A continuing effort to improve availability of specialist palliative care are Palliative Care@home (PaTz) groups, initiated to support community-based healthcare professionals in providing generalist palliative care. Family physicians and community nurses within the same region convene with a palliative care specialist 6 times / year to timely identify patients in a palliative care trajectory and anticipate their preferences and needs. These PaTz groups aim to improve quality of palliative care through coordination, continuity, interdisciplinary communication and professional development in the community. PaTz was shown to improve systematic identification of palliative care patients within the family physician's practice, effective communication with patients in palliative care and interdisciplinary communication in the primary care setting.[72-74] However, this study also reports that further implementation of PaTz is hindered by family physicians' and community nurses' perceived lack of time, lack of financial compensation and additional administrative burden.[72]

In another effort to improve availability and continuity of palliative care across care settings, four regional palliative care networks in the Netherlands initiated implementation of integrated specialist palliative care services. A recent study reported on the process of its development and identified several barriers and facilitators.[75] The issue of governance of such a multi-organisational service and of aligning different goals, views and reimbursement systems were considered impeding factors. More specifically, barriers included the lack of evidence-based guidance on how to organise such a service; unsupportive management of the involved care organisations; different financial reimbursement systems for hospital and out-of-hospital care as well as monodisciplinary reimbursement based on fee-for-service instead of on value or quality. Facilitators consisted of supportive management, as well as professional oncology standards and the NQFPC emphasising the importance of coordination and continuity of care for quality palliative care across care settings.[75] Similar barriers and facilitators were reported in our survey assessing the development and implementation of specialist palliative care teams.[48]

The organisational, financial and regulatory barriers illustrated in these studies are in line with the impeding factors previously described in the implementation of palliative care, in both the Netherlands and other European countries.[76 77 62 78] The Dutch Healthcare Authority (NZa) has recognised the complexity of reimbursement issues for integrated palliative care provision across care settings and new policies are considered to address them on a national level in the next decade.[79 80]

Equitable accessibility of palliative care

In the Netherlands, 70% of about 150,000 annual decedents concerns patients diagnosed with a life-threatening or life-limiting illness. During their illness trajectory, these patients may be presumed to have had palliative care needs.[81]

Results in this thesis show that timely provision of both generalist and specialist palliative care are associated with less potentially inappropriate end-of-life care.[35 36] However, our findings also indicate only 39% of 43,067 patients who died with cancer in 2017 received timely (> 1 month before death) generalist or specialist palliative care and annually less than 1% of all hospitalised patients is referred to specialist palliative care teams.[35 47 48] For the majority of these teams (55%) referrals mostly only occurred for patients in their last month of life. Moreover, the majority of referred patients comprised patients with cancer as most specialist palliative care teams reported non-oncology referrals of 20 - 40%.[47]

Our findings implicate a lack of equitable access to palliative care, i.e., access for all patients with a life-threatening or life-limiting illness or frailty, attuned to the individual complexity of their multidimensional needs. The next paragraphs will consider some factors that may contribute to this **limited accessibility of palliative care** as well as ongoing efforts to improve it.

Impeding factors to accessibility of palliative care

- *Lack of support for identification, needs assessment or referral:*

Supporting palliative care generalists in improving access to palliative care starts with increasing their awareness of its benefits and improving timely identification of patients in need of general or specialist palliative care. Findings in this thesis indicate that hospital-based specialist palliative care teams that participate in other departments' multidisciplinary team meetings, provide dedicated outpatient clinics and provide community education appear to achieve this, as these characteristics are associated with high referral rates (>1% of total annual hospital admissions). Moreover, these teams reach more patients at an earlier time in their palliative care trajectory.[47] Unfortunately this was true for only 27% of all specialist palliative care teams.

Most healthcare professionals have been shown to lack knowledge of the broad applicability of palliative care and how and when to initiate it.[61 82] In addition, a systematic review reported a number of specific barriers that contribute to the limited access to palliative care for non-oncology diagnoses such as COPD and chronic heart failure (CHF): their unpredictable illness trajectory, prognostic uncertainty, the public perception of both diseases as benign, and a lack of effective communication about end-of-life care issues combined with a lack of adequate professional communication skills and unwillingness to disclose sensitive information.[83] Instruments for the identification of patients with palliative care needs (e.g. use of the Surprise Question),[84 85] formal screening criteria (e.g. SPICT),[86] or specialist palliative care referral triggers (e.g. Risk Assessment for palliative care needs)[87] have been shown to support generalist palliative care professionals in selecting patients for referral and were significantly associated with higher referral rates.[3] Although late referrals or a wish to increase referrals were the most commonly cited reasons for their implementation,[88] and international consensus-based criteria have been defined for early referral to dedicated outpatient palliative care clinics,[89] our results show a great variety in use of assessment tools in Dutch hospitals and no formal standards for referral have been implemented yet.[47 48]

- *Lack of qualifications for specialists in palliative care:*

Another factor that may contribute to inequity for patients in a palliative care trajectory is the great variety in the level of clinical experience and specialist palliative care training of physicians and nurses residing on the specialist palliative care teams.[47 48] Our results show that a higher level of education is associated with high referral rates (>1% of total annual hospital admissions) to these teams. This finding is in line with other international studies. A survey focusing on integration of palliative care and oncology among 183 institutions across the world noted that a lack of adequately trained specialist palliative care physicians and nurses was one of the most common barriers to palliative care access and development.[90] Although Dutch professional oncology standards advise all members of the specialist palliative care team to be specifically trained,[36] the competencies required to qualify as a specialist in palliative care have not been defined nor are they accredited in a dedicated medical or nursing (sub)specialty in the Netherlands. Only family physicians and elderly care physicians can register palliative care as a 'special area of competence' with an adhering set of training requirements and qualifications.[91] Subsequently, specialist palliative care teams do not have a uniform level of excellence and funding of specialist palliative care teams or reimbursement for provided care is not naturally forthcoming.[48]

Ongoing efforts to improve accessibility

- *Addressing society's cultural values and beliefs:*

The Council of Public Health & Society has recently advised the Ministry of Health, Welfare and Sport on end-of-life care policies and on addressing our society's culture of silence around death,[92] [93] and the Foundation for Idealistic Advertising (SIRE) has recently launched a national publicity campaign 'Let's talk about death'.

- *Support for identification, needs assessment or referral:*

To improve equitable access to palliative care for patients with CHF researchers developed and validated the I-HARP tool (Identification of patients with HeARt failure with Palliative care needs) with support of healthcare professionals, patients and informal caregivers.[94] The resulting tool supports healthcare professionals to timely recognise palliative care needs in patients with CHF and provide generalist palliative care.[95] To improve accessibility of palliative care for patients with COPD the COMPASSION study assesses the effectiveness of palliative care integration into COPD-care in a cluster randomised trial and studies which strategies may optimize the implementation of integrated palliative care.[96]

To support healthcare professionals in oncology with timely identification, needs assessment and possibly referral to specialist palliative care the TIPZO project (Timely Integration of Palliative Care and Oncology) currently studies development and implementation of a clinical palliative care pathway for oncology.

- *Establishing qualifications for specialists in palliative care:*

Improving equitable accessibility of person-centred palliative care in an integrated generalist and specialist palliative care model as described by both Quill et al. and Henderson et al. requires well trained generalists and specialists in palliative care that can support each other, according to the complexity of patients' palliative care needs.[51 97] To address the educational barriers impeding equitable access to specialist palliative care on a national level, the Netherlands Organisation for Health Research and Development (ZonMw) has extended their funding of the Improving Education in Palliative Care (O^2PZ) project for additional whole-sector development of consensus-based qualifications for specialists in palliative care. Moreover, the Dutch Nurses & Professional Carers Association (V&VN) recently published their educational framework for designated palliative care nurses based on the eight key elements of the NQFPC.

Key elements of quality palliative care prioritised for integration with regular care

The NQFPC was developed to improve the availability and equitable accessibility of high-quality palliative care for all people with life-threatening illnesses or frailty and their families, in adherence to patients' and their families' values, wishes, and needs.[54 98-101] Patients have indicated they like healthcare professionals to know their values, preferences and needs at the right moment, for their family to be involved in their care and to receive appropriate support for physical or psychological symptoms or social and existential needs provided by competent healthcare professionals. Moreover, they want to be able to die at the place of their choice with the appropriate support.[98 99] The standards in the NQFPC that address both nationally and internationally identified barriers to achieving these preferences were selected as **key elements** for prioritised integration in regular health care (see also Table 1).[76 62 102-105] Early **identification** of patients in a palliative care trajectory[83] and a subsequent discussion focusing on **shared decision making and advance care planning**[98 100 103] contribute to acknowledging the values, preferences and needs of the patients and their families. Agreements reached by patients and their healthcare professionals should be recorded in an (electronically available) **individual care plan**. This ensures the patient's sense of autonomy and control over his care as long as possible and enables healthcare professionals to be responsible for **coordination and continuity** of the desired care at the preferred location.[62 102 105] Being able to provide this person- and family-centred quality palliative care requires **effective communication**,[103] and **expertise** through education and training[56] on the part of the healthcare professionals involved, along with attention for their own personal **work-life balance** whilst providing this emotionally demanding care.[106]

Efforts for integration of key elements in clinical practice

In support of international randomised and matched controlled studies that have demonstrated the positive effects of early palliative care,[25-31] the results in this thesis demonstrate the associations between generalist and specialist palliative care provision and less potentially inappropriate end-of-life care in the Netherlands.[35 36] Furthermore, we presented key elements that are expected to improve organisation and delivery of quality palliative care provision.[54] However, our findings do not provide insight into the effectiveness of integration of the key elements in clinical practice.

The recent TAPA$ study (TrAnsmural PAlliative care with appropriate reimbur$ement) assessed palliative care provision in six regional palliative care initiatives in the Netherlands that had incorporated five or more key elements of the NQFPC in their care and coordinated palliative care across care settings.[107-109] Patients provided with palliative care within these initiatives ($n = 210$) were matched to patients provided with standard care ($n = 210$) based on age, sex, diagnosis, year of death and region of residence. Results aligned with findings in this thesis and demonstrated significantly less potentially inappropriate end-of-life care for patients within the palliative care initiatives compared to patients in the control group (14.8% vs 33.8% respectively, $p < 0.05$).[35 36] More specifically, patients within the initiatives were less often admitted to the hospital for > 14 days (3.3% vs 11%, $p < 0.05$), less often admitted to ICU (0.5% vs 10%, $p < 0.05$), and a smaller proportion died in the hospital (8.1% vs 22.4%, $p < 0.05$). In an additional qualitative assessment healthcare professionals within the initiatives indicated that they experienced added value of specialist palliative care for both patients and caregivers as for healthcare professionals, more time for shared decision making and increased awareness for advance care planning, easier and improved interdisciplinary coordination, mutual professional development, and increased confidence amongst patients and their families in the support available to them. [95]

However, in line with the previously mentioned study that followed the start of integrated specialist palliative care services in four regional palliative care networks in the Netherlands,[75] the complexity of governance within the participating initiatives and of aligning different goals, views and reimbursement systems were considered impeding factors.[107] These preliminary results seem consistent with the results presented in this thesis and therefore support our assumption that incorporation of key elements of the NQFPC in clinical practice will diminish the perceived barriers for patients in a palliative care trajectory and their families.[54] Considering these findings, palliative care provided according to the key elements of the NQFPC may be expected to maximise the value of care for patients and their families and may limit the cost of healthcare through less healthcare utilisation at the end of life. As such, it can realise the principles of value based healthcare[110] and bring within reach a person-centred healthcare system that focuses on appropriate care, as has been called for by the National Health Care Institute and the Dutch Health Care Authority.[111] Recently, the Ministry of Health, Welfare and Sport initiated a second National Palliative Care Programme to improve integration of key elements of palliative care into regular care.

Recommendations for clinical practice, education, policy and research

Integration of the key elements of the National Quality Framework for Palliative Care with regular care aims to improve organisation and delivery of quality palliative care and achieve quality of life and quality of end-of-life care for patients and their families, in collaboration with all palliative care generalists and specialists involved. Impeding factors as well as efforts to achieve better integration of palliative care and regular care were discussed in relation to the results presented in this thesis.

For integration of person-centred palliative care, the model proposed by Valentijn et al. has been used in several studies.[112-114] In its essence, the model distinguishes six elements of integration; clinical, professional, organisational, system, functional, and normative integration. To enhance its use, the elements of integration are presented at micro-level, meso-level, and macro-level:

- Micro-level: collaboration between patient and healthcare professional (clinical integration)
- Meso-level: collaboration between professionals and organisations (professional integration, organisational integration),
- Macro-level: laws, rules and regulations (system integration) that impact all levels of collaboration.

The balance between normative or cultural aspects and functional or structural aspects of integration determines the effectiveness of the collaboration and whether intended clinical outcomes will be realised.

In table 2 all clinical, educational and policy recommendations of this thesis are presented at micro-, meso- or macro level and categorised according to the six elements of the Valentijn-model.[113] To present the broader perspective, they are related to other aspects required for successful integration outside the scope of the results presented in this thesis. Recommendations following results in this thesis are subsequently explained.

Quality palliative care for all patients with life-threatening illness or frailty in a generalist – specialist palliative care model					
	Micro-level	Meso-level			Macro-level
	Clinical integration	Professional integration		Organisational integration	System integration
Palliative care Pathway ↓	**Identification** of patients and structural assessment of their palliative care needs on a physical, psychosocial and existential level	Basic **education** for competencies to provide palliative care according to key elements of NQFPC	Awareness of own qualities and l imitations with respect to palliative care. Openness towards skills and expertise of palliative care specialists **Work-life balance**	Provision of (time and funding for) palliative care training and **education** for all healthcare professionals	Health policy for mandatory palliative care education in all healthcare education
	Effective communication with patients and families about their values, preferences and needs in the context of quality of life and end-of-life care (**shared decision making and advance care planning**)			Assessment tools incorporated in electronic patient management system Referral triggers incorporated in patient management system	Inform general public about benefits of palliative care Address society's culture of concealment of death
	Early referral of patients with complex palliative care needs for co-management with palliative care specialists	Specialist palliative care provision in: - multidisciplinary team-meetings with generalists - dedicated outpatient palliative care clinics - community education of generalists and public		Adequate staffing and training of specialist palliative care teams Governance model for organisation of coordinated care across care settings	Define competencies required to qualify as a specialist in palliative care Incorporate both provision of generalist palliative care according to the key elements of the NQFPC and requirements for composition and competencies of specialist palliative care teams in professional standards
	Coordination & continuity of care with an electronically accessible **individual care plan** available across care settings	Interdisciplinary **coordination & continuity of care** with an electronically accessible **individual care plan** available across care settings		Incorporation of electronic individual care plan in patient management systems	Health insurance contracts for value-based multidisciplinary healthcare across care settings Health policy for palliative care in Mandatory Data-exchange Act (Wegiz)

▨ Normative integration
▨ Functional integration

Bold text: key elements of Netherlands Quality Framework for Palliative Care
Orange text: recommendations following results in this thesis

Table 2. Integrated recommendations following the results presented in this thesis. Adapted from Valentijn et al.[100]

Recommendations for clinical practice

Palliative Care Pathway

A clear palliative care pathway, that can be integrated with regular care across care settings, should support and accommodate all healthcare professionals that are generalists in palliative care, whether they work in the community or in hospitals.

The eight key elements of the National Quality Framework for Palliative Care should be incorporated as the backbone of this pathway.

Identification

All healthcare professionals should be able to identify patients in a palliative care trajectory. Quality generalist palliative care starts with acknowledging and discussing with patients and their families the change in goals of care and exploring values and preferences of both.

Subsequently, they should systematically assess and manage their palliative care needs in the physical, psychosocial and existential dimensions (micro-level).[1]

To facilitate and standardise this process for all healthcare professionals, a prompt for the Surprise Question,[84 85] and a symptom assessment tool such as USD-4D[115 116] should be incorporated in the electronic patient management systems (meso-level).

Effective communication

All healthcare professionals should communicate effectively with patients in a palliative care trajectory and their family, to discuss values, preferences and needs for quality of life and end-of-life care in a language that is mutually understandable. A continuous process of care and service across care settings for patients and their families can only be achieved through clear and effective communication between patients and their healthcare professionals, and amongst professionals as well as amongst organisations (micro-, meso-level).

Early referral of patients with complex palliative care needs

All healthcare professionals should be able to identify patients with complex palliative care needs for co-management with specialist in palliative care (micro-level).

When complex palliative care needs are identified specialist palliative care should be available for consultation in all care settings (meso-level).

To facilitate and standardise this process for all healthcare professionals, referral triggers for specialist palliative care (e.g. Risk Assessment for complex palliative care needs)[87] should be incorporated in the electronic patient management systems (meso-level).

Coordination & continuity of care

During their illness, patients in a palliative care trajectory have varying needs for which different healthcare professionals and informal caregivers can be involved simultaneously or over time. To provide continuous quality palliative care across care settings, based on the patient's values, preferences and needs, this care should be coordinated at an individual level (micro level) and between healthcare professionals and care settings (meso level). To support this, each patient in a palliative care trajectory should have an individual care plan, which is kept with the patient and is adjusted when necessary during the disease process.[1] The individual care plan facilitates keeping the patient, his family, healthcare professionals and informal caregivers aligned to provide the right care, in the right place, at the right time, by the right healthcare professional at all times (micro-level).

Preferably, the individual care plan is electronically accessible to all involved.[1]

Specialist palliative care provision

To improve their accessibility, palliative care specialists should increase their availability and visibility by participating in hospital- and community based multidisciplinary team meetings, providing hospital- or community based outpatient clinics (i.e., anderhalvelijn poli) and providing education for both healthcare professionals and general public across care settings (meso level).[47 82] To that end, hospital-based specialist palliative care teams should be adequately staffed and trained (meso-level).[44]

Recommendations for education

Future healthcare professionals

To anticipate the foreseen increase in patients with palliative care needs, all future healthcare professionals should be trained as generalists in palliative care according to the qualifications in the educational competencies framework.[71]

Practicing generalists in palliative care

To answer the call from WHO and the Council of Europe for standardised availability, equitable accessibility, and high-quality palliative care as a human right and the strengthening of generalist and specialist palliative care as components of integrated care throughout the patient's life,[117 118] all practicing healthcare professionals should be trained to obtain basic competencies for provision of generalist palliative care according to the key elements of the National Quality Framework for Palliative Care (meso-level).[54]

Organisations should allow time and funding for all generalists in palliative care to participate in palliative care training and education (meso-level).

Practicing specialists in palliative care

Better staffing and training of specialist palliative care teams is associated with a higher referral rate, suggesting better and earlier accessibility for patients with complex palliative care needs. To improve overall accessibility to specialist palliative care, all palliative care specialists should be trained and educated to meet consensus-based qualifications.

Recommendations for policy

Despite all initiatives and positive results on micro and meso level previously discussed in this chapter, barriers and impeding factors to equitable accessibility of palliative care that meets national standards of quality in all settings cannot be resolved without institutional, government, regulatory, and payer support and involvement.[119]

Generalist palliative care mandatory requirement in healthcare education

In view of the currently limited availability of generalist palliative care and the underutilisation of specialist palliative care,[35 36 47] government policy should stipulate palliative care education as mandatory in all healthcare education. The consensus-based educational competencies framework can be used as guidance to prepare all healthcare professionals for the foreseen increase in patients with palliative care needs.[112 120]

Consensus-based qualifications and accreditation for palliative care specialists

Considering the great variety in the level of clinical experience and specialist palliative care training of physicians and nurses residing on the specialist palliative care teams,[47 48] the competencies required to qualify as a specialist in palliative care should primarily be defined and accredited in dedicated medical and nursing (sub)specialties.[91] This will not only improve the quality, availability and accessibility of palliative care for patients with complex care needs, but it will also improve the educational quality of rotations and fellowships for generalists, facilitate health insurance contracting, attract healthcare professionals to train in this field of care and help to further develop the palliative care profession through research.

Professional oncology standards (SONCOS normering)

Professional oncology standards as well as standards for non-oncological diseases should incorporate provision of generalist palliative care according to the key elements of the National Quality Framework for Palliative Care, in support of the generalist-specialist palliative care model. In addition, requirements for specialist palliative care as listed in current professional oncology standards should be expanded with more explicit requirements for constellation and qualifications of specialist palliative care teams (macro level).[121]

Electronically available individual care plan

To ensure the right care, in the right place, at the right time, by the right healthcare professional a patient's values, preferences and needs should be known wherever the patient resides. Therefore, an individual care plan should be electronically available across care settings. To support this development the so-called roadmap in the Mandatory Data-exchange Act (Wegiz) should be extended and prioritised for palliative care (macro level).

Recommendations for research

Effectiveness of the integration of key elements

Results of the TAPA$ study support that integration of the key elements of the National Quality Framework for Palliative Care diminishes potentially inappropriate end-of-life care.[36 54 109] Further research should address the effect of broad integration of these key elements in clinical practice on effectively diminishing the perceived barriers and improving both quality of life and end-of-life care for patients in a palliative care trajectory and their families (micro level).

Quality Indicators to measure and improve the integration of palliative care

The concept of integrating palliative care and regular care has gained wide professional and scientific support and a global consensus on what constitutes integration of specialist palliative care teams has been defined.[122] Consensus-based quality indicators measuring integration of generalist and specialist palliative care should be defined to support a quality-improvement PDCA cycle for healthcare organisations (macro-level).

Palliative care dashboard in electronic patient management system

Studying end-of life care in vulnerable populations is ethically and methodologically challenging.[5] Health care administrative data registering completion of an individual care plan or start of a care pathway for the dying patient in relation to healthcare utilisation in the last month before death may support organisations and their healthcare professionals to better understand the quality of care provided, without burdensome questionnaires or extra administration.[123] How presentation of these data in a palliative care dashboard for organisations or healthcare professionals may affect quality of palliative care and end-of-life care should be evaluated (meso-level).

Palliative care and potentially inappropriate end-of-life care in patients with non-oncological diseases

A number of barriers specific for non-oncological diseases like COPD and CHF, such as unpredictable illness trajectory with acute exacerbations and prognostic uncertainty, contribute to lower availability and accessibility of palliative care for these patients than for patients with advanced cancer.[83] Whether palliative care provision is similarly associated with quality of end-of-life care for patients with COPD or CHF as for patients with advanced cancer should be assessed (macro-level).[35 36]

Relation between Quality Indicators for potentially inappropriate and appropriate care and patients' and families' perceived Quality of care and Quality of life

International consensus-based quality indicators for inappropriate and appropriate care have been designed to measure and improve quality of end-of-life care in population-based studies.[15] Whether patients and their families in the Netherlands agree these quality indicators adequately represent their perceived quality of care and quality of life should be evaluated (micro-level).[103 124]

Required workforce capacity of palliative care specialists

Results in this thesis as well as other studies show that better staffing of specialist palliative care teams seems associated with higher referral rates of patients with palliative care needs and access to patients at an earlier moment in their disease trajectory.[2 3] How many palliative care specialists are needed to implement and support an integrated palliative care model? To anticipate future decennia with increasingly older populations and more complex care needs research should focus on an appropriate service model for palliative care provision in the Dutch healthcare system (meso-level). [20 51 52] This information would allow health service decisionmakers and educational institutions to plan resources accordingly (macro-level).[53]

Continuity of care across care settings

A recent population-based study indicated that receiving inpatient palliative care was associated with experiencing more continuity of community palliative care after discharge.[66] This may well have been a contributing factor to the association between hospital-based specialist palliative care provision and less potentially inappropriate end-of-life care presented in this thesis.[36] Research should assess such relations in continuity of care in the Dutch healthcare system to identify potential for improvement.

Conclusion

Healthcare systems should focus on the timely integration of palliative care across all levels of health and social care disciplines in order to anticipate the foreseen increase in patients with non-communicable chronic diseases and their health-related suffering.[23 97 125-127] The Netherlands Quality Framework for Palliative Care (NQFPC) was developed in order to address identified barriers and improve the organisation and delivery of person-centred **quality palliative care for all** patients with life-threatening illness or frailty and their families, **towards death, while alive.** Eight key elements of this framework were prioritised for integration of palliative care into regular care. Results in this thesis, together with international intervention studies, underpin the potential benefits of timely provision of both generalist and specialist palliative care for patients in a palliative care trajectory and their families. However, they also clearly show an underutilisation of palliative care due to limited availability and accessibility of palliative care services. Dedicated educational programmes should improve the skills and competencies of all healthcare professionals and in collaboration with all institutional levels optimal continuity of quality palliative care should be guaranteed. For the sake of patients, their families and public health, as a society we should **WANT IT!**

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Chapter 8

Summary

This chapter is a summary of the main findings in this thesis. A Dutch summary can be found in the Appendices.

Background

The demography of ageing and an exponential growth of curative and rehabilitative treatments in the last decades have resulted in older populations with more complex care needs.[1] Non-communicable chronic diseases are currently the leading cause of morbidity and mortality in high income countries,[2] where approximately 75% of people die from life-threatening and life-limiting illnesses, such as cancer, dementia, obstructive lung disease, heart disease and neurodegenerative diseases, with evolving and increasing health care needs.[3 4] Meeting these needs is putting progressive demands on society and its healthcare systems.[4]

Palliative care

Palliative care is defined as a person-centred 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 existential.[5]

Integration of specialist palliative care into regular care *improves quality of life, symptom burden* and *patient and caregiver satisfaction* for patients with advanced cancer and other life-limiting diseases.[6-14] Moreover, palliative care *diminishes potentially inappropriate care at the end of life,* such as visits to the emergency department, hospital- or ICU admissions and hospital death.[7 9 13 15 16] The Dutch healthcare system strives towards an integrated generalist and specialist palliative care model,[17] where core elements of palliative care such as basic symptom management and tailoring treatments to a patient’s goals, are provided by all healthcare professionals as part of regular care (generalist palliative care). Other elements of palliative care require more complex skills, such as negotiating challenging family meetings, addressing veiled existential distress, and managing refractory symptoms. These are provided by healthcare professionals specifically trained in palliative care (specialist palliative care). Provision of person-centred palliative care in this integrated model requires continuous co-operation and coordination between generalists and specialists in palliative care, so that they support each other, according to the complexity of patients’ palliative care needs.[18]

Barriers to the provision of person-centred palliative care

Within our predominantly biomedical healthcare model that is focused on cure, it currently still appears challenging to structurally provide optimal, person-centred palliative care.[19-22] Reasons for continuing treatments to prolong life at the end of life and not providing person-centred palliative care seem to be rooted in a culture of non-abandonment, treatment as a default mode, lack of training or emotional reluctance to talk about worsening of prognosis and death,[22] as well as fragmented healthcare systems,[23 24] limited interdisciplinary teamwork[25] and financial incentives being directed at fee for service instead of value-based healthcare.[22] As a result, a substantial number of patients in a palliative care trajectory continue to receive inappropriate treatments at the end of their lives, often leading to poor quality and high-cost care.[19 26 27] Improving their quality of end-of-life care is a priority both for patients and their families as for public health.[22 28]

Aims of this thesis

This thesis aimed to gain a better understanding of the **value, availability and accessibility of palliative care** in a mixed generalist specialist palliative care model as it is operated in the Dutch health care system. In addition, it aimed to provide insight into the process of developing a national quality framework for palliative care and to present the **key elements of quality palliative care** for integration with regular care.

Availability and accessibility of hospital-based specialist palliative care teams, their development over time and characteristics associated with high referral rate.

In 2014 the Dutch Federation of Oncological Societies (SONCOS) stated that, within three years, each hospital should have a palliative care team.[29] In a national cross-sectional survey among all Dutch hospitals in 2015 **(chapter 2)** we studied the number of hospitals with a specialist palliative care team or other palliative care services, and the characteristics of these teams.

In total, 74 hospitals responded (80%). The number of hospitals with a specialist palliative care team providing inpatient consultation services had increased from 39% in 2013 to 77% in 2015. With a mean referral rate of only 0.6% of total annual number of hospital admissions, their involvement with patients with a serious life-threatening or life-limiting illness was low, as international data indicate that hospital referral rates to specialist palliative care may be expected to be about 4-5%.[30 31] There were substantial differences between teams regarding the number of consultations per year (ranging from 2 to 680), team organisation and disciplines represented on the teams. Most variation in team organisation concerned quality criteria for the availability of teams, their consultation process and the educational requirements for team members. The most common disciplines on the teams were nurses (72%) and nurse practitioners (54%), medical specialists in internal medicine (90%) and anaesthesiology (75%) and spiritual caregivers (65%). In most cases, the medical specialists did not have labelled hours available for their work as palliative care consultant, whereas nurses and nurse practitioners did.

In 2018, we repeated the cross-sectional survey among all Dutch hospitals **(chapter 3)**. While the number of hospitals with a specialist palliative care team had increased to 94%, the mean referral rate to these teams remained low, showing only a marginal increase to 0.85%. Moreover, for the majority of teams less than 4 out of 10 referrals were non-oncology referrals (71%) and referrals still mostly only occurred for patients in their last month of life (55%). To identify how accessibility to specialist palliative care teams may be improved, we explored characteristics and level of integration of teams with high and low referral rates and assessed relations between them. We found that higher referral rates (>1% of total annual hospital admissions) were associated with teams being more mature (existence > 3 years), better staffed (more designated hours/week for nurses and physicians on the team) and better trained (less nurses with just basic training), and with having access to patients at an earlier moment in their disease trajectory. This appears associated with a more outreaching character of these specialist palliative care teams as they more often provide outpatient palliative care clinics, participate in multidisciplinary team meetings of other departments and provide education in the community in addition to in-hospital education.

Association between palliative care and potentially inappropriate end-of-life care

To assess the value of palliative care we studied the relation between quality end-of-life care and the provision of palliative care. We did this by retrospectively comparing quality indicators for potentially inappropriate end-of-life care of patients with cancer who received no palliative care at all or only in their last month of life, with patients who received palliative care before their last month of life.

In a nationwide study **(chapter 4)**, we collected data from a national administrative health insurance database for patients who were diagnosed with or treated for cancer during the year preceding their death in 2017. Outcomes were measured over the last month of life, using six quality indicators for potentially inappropriate end-of-life care pertaining to ≥2 ED-visits, ≥2 hospital admissions, >14 days hospitalisation, ICU-admission, chemotherapy and hospital death.

Among 43,067 deceased adults with cancer, we demonstrated that more than one third experienced potentially inappropriate care in their last month of life. Patients who received palliative care prior to their last month of life (39%) were five times less likely to experience potentially inappropriate care in their last month of life than patients who did not (16% vs 45%, adjusted OR 0.20 (95% CI 0.15 to 0.26)). As palliative care provision in most cases consisted of generalist palliative care (88%), this appeared to support the complementary potential of generalist and specialist palliative care in a mixed palliative care model.

In this nationwide study hospital-based specialist palliative care may have been under-registered due to complex reimbursement regulations in 2017. Therefore, to assess the specific value of specialist palliative care, we subsequently applied a similar study-design to administrative hospital data of two acute care hospitals **(chapter 5)**. Among 2,603 deceased adults with cancer who died in 2018 or 2019 more than one fourth experienced potentially inappropriate care in their last month of life. Patients with involvement of the specialist palliative care team (13%) before their last month of life were nearly two times less likely to experience potentially inappropriate care in their last month of life than patients without involvement of the specialist palliative care team or no involvement until their last month of life (19% vs 28%, adjusted OR 0.55 (95% CI 0.42 to 0.74)). Initiation of specialist palliative care in the outpatient setting seemed to enhance this result (adjusted OR 0.32 (95% CI 0.17 to 0.61)), whereas most patients received specialist palliative care in the inpatient setting (74%).

Development of a national quality framework for palliative care and its key elements for integration

The overall results of these studies substantiate the necessity to improve availability and accessibility of palliative care, attuned to the individual complexity of patients' needs. In 2015 the Dutch Society of Professionals in Palliative Care (Palliactief) and the Netherlands Comprehensive Cancer Organisation (IKNL) initiated the development of the Netherlands Quality Framework for Palliative Care to improve the organisation and delivery of person-centred palliative care **(chapter 6)**.

Using a whole-sector approach, we invited patients, healthcare professionals from various disciplines, health insurers, and policymakers to participate and pool their ambitions, information, resources, knowledge and skills. To construct the quality framework a bottleneck analysis of palliative care provision and a literature review were conducted. Six core documents were used in a modified Delphi technique to build the framework with an expert panel, while stakeholder organisations were involved and informed in round-table discussions. This whole-sector approach has succeeded in gaining broad consent and recognition for provision of high-quality, person-centred palliative care in a mixed generalist specialist model that can be integrated across all care settings. The Netherlands Quality Framework for Palliative Care was launched in 2017.

Patients in a palliative care trajectory have indicated that they would like healthcare professionals to know their values, preferences and needs at the right moment, for their family to be involved in their care and to receive appropriate support for physical or psychological symptoms or social and existential needs provided by competent healthcare professionals. Moreover, they want to be able to die at the place of their choice with the right care.[32 33]

Eight key elements from the Netherlands Quality Framework for Palliative Care were prioritised for integration to ensure provision of this person-centred palliative care.

Early **identification** of patients in a palliative care trajectory[34] and a subsequent discussion focusing on **shared decision making** and **advance care planning**[33 35 36] contribute to acknowledging the values, preferences and needs of the patients and their families. Agreements reached by patients and their healthcare professionals should be recorded in an (electronically available) **individual care plan.** This ensures patients' sense of autonomy and control over their care as long as possible and enables healthcare professionals to be responsible for **coordination and continuity** of the desired care at the preferred location.[23 37 38] Being able to provide this person- and family-centred quality palliative care requires **effective communication,**[36] and **expertise** in palliative care through education and training[39] on the part of the healthcare professionals involved, along with attention for their own personal **work-life balance** whilst providing this emotionally demanding care.[40]

General Discussion

The general discussion **(chapter 7)** includes the summarised results of the studies reported in this thesis, a critical reflection on the methods used and a broader perspective on the findings resulting in recommendations for clinical practice, education, policy and research.

The main findings show that **timely provision of generalist and specialist palliative care is associated with significantly less potentially inappropriate end-of-life care for patients with advanced cancer in the Netherlands.**[41 42] Additionally, **outpatient initiation of specialist palliative care appears to strengthen this association.**

Unfortunately, the majority of patients with cancer received no generalist or specialist palliative care or only in their last weeks or even days of life.[41 42] Moreover, although specialist palliative care teams were found to be available in almost all hospitals,[43] referrals to these teams were consistently low, comprised just a small proportion of non-oncology patients and mostly occurred only in the last weeks of life.[42-44] Thus, our findings implicate **a limited availability and accessibility of palliative care** attuned to the individual needs of patients with life-threatening illnesses and their families.

The Netherlands Quality Framework for Palliative Care was developed in order to address identified barriers of providing palliative care and improve the organisation and delivery of person-centred **quality palliative care for all** patients with life-threatening illness or frailty and their families**, towards death, while alive.** Its eight key elements form a pathway that can serve as a practical guideline to aid policymakers, managers and healthcare professionals in integrating palliative care and regular care.

In addition, dedicated educational programmes should improve the skills and competencies of all healthcare professionals and in collaboration with all institutional levels optimal continuity of quality palliative care should be guaranteed. Research should focus on how many palliative care specialists are needed to implement and support an integrated palliative care model in the Dutch healthcare system.[1 18 45] This information will enable health service decisionmakers and educational institutions to plan resources accordingly.[46]

To anticipate the expected increase in patients with life-threatening and life-limiting chronic diseases and their health-related suffering healthcare services should focus on the timely integration of quality palliative care across all levels of health and social care disciplines.[4 6 17 47 48] For the sake of all patients, their families and public health, as a society we should **WANT IT!**

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Achtergrond

De vergrijzing en een exponentiële groei van curatieve behandelingen in de afgelopen decennia hebben geleid tot een oudere bevolking met complexere zorgbehoeften.[1] Niet-overdraagbare chronische ziekten zijn momenteel de belangrijkste oorzaak van ziekte en sterfte in welvaartslanden,[2] waar ongeveer 75% van de mensen sterft aan levensbedreigende en levensbeperkende ziekten zoals kanker, dementie, obstructieve longziekten, hartziekten en neurodegeneratieve ziekten, met veranderende en toenemende zorgbehoeften.[3 4] Het voldoen aan deze behoeften stelt steeds hogere eisen aan de samenleving en haar gezondheidszorg.[4]

Palliatieve zorg

Palliatieve zorg wordt gedefinieerd als een persoonsgerichte benadering die de kwaliteit van leven verbetert van patiënten en hun naasten die te maken hebben met een levensbedreigende aandoening, door het voorkomen en verlichten van lijden door middel van vroegtijdige signalering en zorgvuldige beoordeling en behandeling van pijn en andere problemen van lichamelijke, psychosociale en spirituele aard.[5]

De integratie van gespecialiseerde palliatieve zorg in de reguliere zorg *verbetert de kwaliteit van leven*, *vermindert de symptoomlast* en *vergroot de tevredenheid van patiënten* met gevorderde kanker en andere levensbeperkende ziekten *en hun mantelzorgers*.[6-14] Bovendien *vermindert* palliatieve zorg *potentieel niet-passende zorg aan het einde van het leven,* zoals bezoeken aan de spoedeisende hulp, ziekenhuis- of IC-opnames en sterfte in het ziekenhuis.[7 9 13 15 16] De Nederlandse gezondheidszorg streeft naar een geïntegreerd generalistisch en specialistisch model voor palliatieve zorg,[17] waar basiselementen van palliatieve zorg, zoals eenvoudige symptoombestrijding en het afstemmen van behandelingen op de doelen van de patiënt, door alle zorgverleners worden geleverd als onderdeel van de reguliere zorg (generalistische palliatieve zorg). Voor andere elementen van palliatieve zorg, zoals het omgaan met complexe gezinssituaties, het verkennen van verborgen existentiële nood en het behandelen van refractaire symptomen zijn grotere vaardigheden vereist en zijn zorgverleners beschikbaar die specifiek zijn opgeleid in palliatieve zorg (specialistische palliatieve zorg). Het verlenen van persoonsgerichte palliatieve zorg in dit geïntegreerde model vereist voortdurende samenwerking en coördinatie tussen deze generalisten en specialisten in palliatieve zorg, afgestemd op de complexiteit van de palliatieve zorgbehoeften van patiënten.[18]

Belemmeringen in het verlenen van persoonsgerichte palliatieve zorg

Aangezien ons huidige, overwegend biomedische gezondheidszorgmodel veelal gericht is op genezing, blijkt het nog altijd een uitdaging om structureel optimale, persoonsgerichte palliatieve zorg te bieden.[19-22] Redenen om rondom het levenseinde door te gaan met levensverlengende behandelingen en geen persoonsgerichte palliatieve zorg te bieden lijken geworteld te zijn in een cultuur van niet-opgeven, van zorgverleners in behandelmodus, en van gebrek aan opleiding of emotionele terughoudendheid om te praten over verslechtering van de prognose en de dood,[22] evenals een gefragmenteerd gezondheidszorgsysteem,[23 24] beperkte interdisciplinaire samenwerking[25] en financiële prikkels die gericht zijn op "fee for service" in plaats van waarde gedreven gezondheidszorg.[22] Als gevolg hiervan blijft een aanzienlijk aantal patiënten met een levensbedreigende aandoening niet-passende behandelingen ondergaan aan het einde van hun leven, hetgeen vaak leidt tot zorg van slechte kwaliteit en hoge kosten.[19 26 27] Verbetering van de kwaliteit van de zorg aan het einde van het leven zou een prioriteit moeten zijn voor zowel patiënten en hun naasten als voor de volksgezondheid.[22 28]

Doelstellingen van dit proefschrift

Dit proefschrift heeft tot doel om beter inzicht te krijgen in de **waarde, beschikbaarheid en toegankelijkheid van palliatieve zorg** in een gemengd generalistisch-specialistisch zorgmodel voor palliatieve zorg zoals dat in de Nederlandse gezondheidszorg wordt gehanteerd. Daarnaast wil het inzicht geven in de totstandkoming van een nationaal kwaliteitskader voor palliatieve zorg en de **essenties van hoogwaardige palliatieve zorg** presenteren voor integratie in de reguliere zorg.

Beschikbaarheid en toegankelijkheid van gespecialiseerde teams palliatieve zorg in ziekenhuizen, hun ontwikkeling in de tijd en kenmerken gerelateerd aan verwijzingen.

In 2014 stelde de Stichting Oncologische Samenwerking (SONCOS) dat elk ziekenhuis binnen drie jaar een team palliatieve zorg zou moeten hebben.[29] In een landelijke enquête onder alle Nederlandse ziekenhuizen in 2015 **(hoofdstuk 2)** onderzochten we het aantal ziekenhuizen met een gespecialiseerd team palliatieve zorg en de kenmerken van deze teams.

In totaal reageerden 74 ziekenhuizen (80%). Het aantal ziekenhuizen met een gespecialiseerd team palliatieve zorg dat klinische consulten verzorgt, was gestegen van 39% in 2013 tot 77% in 2015. Met een gemiddeld verwijzingspercentage van slechts 0,6% van het totale jaarlijkse aantal ziekenhuisopnames was hun betrokkenheid bij patiënten met een ernstige levensbedreigende of levensbeperkende ziekte laag, aangezien het verwijzingspercentage naar gespecialiseerde palliatieve zorg voor ziekenhuizen in internationaal onderzoek ongeveer 4-5% bedraagt.[30 31] Er waren aanzienlijke verschillen tussen de teams wat betreft het aantal consulten per jaar (variërend van 2 tot 680), de teamorganisatie en de disciplines die in de teams vertegenwoordigd waren. De grootste variatie in teamorganisatie betrof de kwaliteitscriteria voor de beschikbaarheid van de teams, hun consultatieproces en de opleidingseisen voor de teamleden. De meest voorkomende disciplines in de teams waren verpleegkundigen (72%) en verpleegkundig specialisten (54%), medisch specialisten interne geneeskunde (90%) en anesthesiologie (75%) en geestelijk verzorgers (65%). In de meeste gevallen hadden de medisch specialisten geen gelabelde uren beschikbaar voor hun werk als consulent palliatieve zorg, terwijl verpleegkundigen en verpleegkundig specialisten dat wel hadden.

In 2018 herhaalden we de enquête onder alle Nederlandse ziekenhuizen **(hoofdstuk 3)**. Hoewel het aantal ziekenhuizen met een gespecialiseerd team palliatieve zorg was toegenomen tot 94%, bleef het gemiddelde bereik van deze teams laag, met slechts een marginale stijging van het verwijzingspercentage naar 0,85%. Bovendien waren voor de meerderheid van de teams minder dan 4 van de 10 verwijzingen niet-oncologisch (71%) en waren ze nog steeds grotendeels voor patiënten in hun laatste levensmaand (55%). Om na te gaan hoe de toegankelijkheid van gespecialiseerde teams palliatieve zorg kan worden verbeterd, onderzochten we de kenmerken en het integratieniveau van teams met hoge en lage verwijzingspercentages en de relaties daartussen. Daaruit bleek dat hogere verwijzingspercentages (>1% van de totale jaarlijkse ziekenhuisopnames) gerelateerd waren aan teams die volwassener (bestaan > 3 jaar), beter bemenst (meer gelabelde uren/week voor verpleegkundigen en artsen in het team) en beter opgeleid (minder verpleegkundigen met alleen een basisopleiding) waren, en aan contact met patiënten op een vroeger moment in hun ziektetraject. Dit lijkt samen te hangen met een meer proactief karakter van deze gespecialiseerde teams palliatieve zorg, omdat ze vaker poliklinieken palliatieve zorg hebben, deelnemen aan multidisciplinaire overleggen van andere afdelingen en naast scholing in het ziekenhuis ook scholing geven buiten hun instelling.

Associatie tussen palliatieve zorg en potentieel niet-passende zorg rondom het levenseinde

Om de waarde van palliatieve zorg te kunnen beoordelen hebben wij de relatie onderzocht tussen de kwaliteit van zorg rondom het levenseinde en het verlenen van palliatieve zorg. Dit hebben we gedaan door retrospectief kwaliteitsindicatoren voor potentieel niet-passende zorg rondom het levenseinde te vergelijken tussen patiënten met kanker die helemaal geen palliatieve zorg ontvingen of alleen in hun laatste levensmaand, en patiënten die palliatieve zorg ontvingen vóór hun laatste levensmaand. In een landelijke studie **(hoofdstuk 4)** verzamelden we in de nationale zorgverzekeringsdatabase (Vektis) gegevens van patiënten die in het jaar voorafgaand aan hun overlijden in 2017 waren gediagnosticeerd met of behandeld voor kanker. Uitkomsten werden gemeten in de laatste maand van het leven, aan de hand van zes kwaliteitsindicatoren voor potentieel niet-passende zorg rondom het levenseinde. Deze hadden betrekking op ≥ 2 ED-bezoeken, ≥ 2 ziekenhuisopnames, >14 dagen

ziekenhuisopname, IC-opname, chemotherapie en overlijden in het ziekenhuis.
Van in totaal 43.067 overleden volwassenen met kanker onderging meer dan een derde potentieel niet-passende zorg in hun laatste levensmaand. Patiënten die palliatieve zorg ontvingen vóór hun laatste levensmaand (39%) hadden vijf keer minder kans op potentieel niet-passende zorg in hun laatste levensmaand dan patiënten zonder palliatieve zorg (16% vs 45%, gecorrigeerde odds ratio (OR) 0,20 (95% CI 0,15 tot 0,26)). Aangezien de verleende palliatieve zorg in de meeste gevallen bestond uit generalistische palliatieve zorg (88%), lijkt dit het complementaire potentieel van een geïntegreerd generalistisch en specialistisch model voor palliatieve zorg te ondersteunen.[17]
In deze landelijke studie was mogelijk sprake van onder-registratie van ziekenhuis gerelateerde specialistische palliatieve zorg, vanwege complexe declaratie regelgeving in 2017. Om de specifieke waarde van specialistische palliatieve zorg te onderzoeken, hebben we vervolgens een vergelijkbare studie uitgevoerd met gebruik van de administratieve zorgdatabases (HiX®) van twee ziekenhuizen **(hoofdstuk 5)**. Van de 2.603 volwassenen met kanker die in 2018 of 2019 overleden, onderging meer dan een kwart potentieel niet-passende zorg in hun laatste levensmaand. Patiënten waarbij het specialistische team palliatieve zorg betrokken was vóór hun laatste levensmaand (13%) hadden bijna twee keer minder kans op potentieel niet-passende zorg in hun laatste levensmaand dan patiënten waarbij het specialistische team palliatieve zorg niet of pas in hun laatste levensmaand betrokken werd (19% vs 28%, gecorrigeerde OR 0,55 (95% CI 0,42 tot 0,74)). Een poliklinische start van specialistische palliatieve zorg leek dit resultaat nog te versterken (gecorrigeerde OR 0,32 (95% CI 0,17 tot 0,61)), terwijl bij de meeste patiënten de specialistische palliatieve zorg gestart werd tijdens een ziekenhuisopname (74%).

Totstandkoming van een nationaal kwaliteitskader palliatieve zorg en haar essenties voor integratie

De algehele resultaten van deze studies onderbouwen de noodzaak om de beschikbaarheid en toegankelijkheid te verbeteren van palliatieve zorg, die is afgestemd op de individuele complexiteit van de zorgbehoeften van patiënten.
In 2015 zijn Palliactief en Integraal Kankercentrum Nederland (IKNL) gestart met de ontwikkeling van het Kwaliteitskader Palliatieve Zorg Nederland om de organisatie en het bieden van persoonsgerichte palliatieve zorg te verbeteren **(hoofdstuk 6)**.
Middels een sector omvattende aanpak hebben we patiënten, zorgverleners uit verschillende disciplines, zorgverzekeraars en beleidsmakers uitgenodigd om deel te nemen en hun ambities, middelen, kennis en vaardigheden te bundelen. Voor het opstellen van het kwaliteitskader werden een knelpuntenanalyse van de palliatieve zorgverlening en een literatuurstudie uitgevoerd. Zes basisdocumenten werden in een aangepaste Delphi-methode gebruikt om met een panel van deskundigen het kader te

bouwen. Daarbij werden organisaties van belanghebbenden betrokken en geïnformeerd in rondetafelgesprekken en consultatie-rondes. Deze sector omvattende aanpak heeft geresulteerd in brede instemming en erkenning voor het bieden van hoogwaardige, persoonsgerichte palliatieve zorg in een generalistisch-specialistisch model dat in alle zorgsettingen kan worden geïntegreerd. Het Kwaliteitskader Palliatieve Zorg Nederland werd in 2017 gelanceerd.

Patiënten in de palliatieve fase hebben aangegeven dat zij graag willen dat zorgverleners op het juiste moment hun waarden, wensen en behoeften kennen, dat hun familie betrokken wordt bij hun zorg en dat zij van deskundige zorgverleners passende ondersteuning krijgen bij lichamelijke of psychische symptomen of sociale en existentiële behoeften. Bovendien willen zij met de juiste zorg op de plaats van hun voorkeur kunnen sterven.[32 33]
Acht essenties uit het Kwaliteitskader Palliatieve Zorg Nederland werden geprioriteerd voor integratie in de reguliere zorg om deze persoonsgerichte palliatieve zorg te kunnen bieden.
Vroege **identificatie** van patiënten in de palliatieve fase[34] en een daaropvolgend gesprek gericht op **gezamenlijke besluitvorming** en **proactieve zorgplanning**[33 35 36] dragen bij aan het erkennen van de waarden, wensen en behoeften van patiënten en hun familie. Overeengekomen afspraken tussen patiënten en hun zorgverleners dienen te worden vastgelegd in een (elektronisch beschikbaar) **individueel zorgplan**, zodat voor patiënten het gevoel van autonomie en controle over hun zorg zo lang mogelijk gewaarborgd blijft en zorgverleners in staat zijn om de **coördinatie en continuïteit** van de gewenste zorg op de plaats van voorkeur op zich te nemen.[23 37 38] Het bieden van deze hoogwaardige persoons- en familiegerichte palliatieve zorg vraagt van de betrokken zorgverleners **effectieve communicatie,**[36] en **deskundigheid** in palliatieve zorg door opleiding en training,[39] alsook aandacht voor hun eigen **persoonlijke balans** bij het verlenen van deze emotioneel veeleisende zorg.[40]

Algemene discussie
De algemene discussie **(hoofdstuk 7)** omvat de samengevatte resultaten van de in dit proefschrift gepresenteerde studies, een kritische reflectie op de gebruikte methoden en een breder perspectief op de bevindingen, resulterend in aanbevelingen voor praktijk, onderwijs, beleid en onderzoek.
De belangrijkste bevindingen laten zien dat in Nederland het **tijdig bieden van generalistische en specialistische palliatieve zorg aan patiënten met gevorderde kanker geassocieerd is met significant minder potentieel niet-passende zorg rondom het levenseinde.**[41 42] Daarbij lijk**t** het **poliklinisch starten van specialistische palliatieve zorg dit resultaat te versterken.**

Helaas kregen de meeste patiënten met kanker geen generalistische of specialistische palliatieve zorg of pas in de laatste weken of zelfs dagen van hun leven.[41 42] En hoewel in bijna alle ziekenhuizen gespecialiseerde teams voor palliatieve zorg beschikbaar bleken te zijn,[43] waren de verwijzingen naar deze teams consistent laag, bestonden ze slechts voor een klein deel uit niet-oncologische patiënten en vonden ze meestal pas plaats in de laatste weken van het leven.[42-44] Zo wijzen onze bevindingen op **een beperkte beschikbaarheid en toegankelijkheid van palliatieve zorg**, afgestemd op de individuele zorgbehoeften van patiënten met levensbedreigende ziekten en hun naasten.

Het Kwaliteitskader Palliatieve Zorg Nederland is ontwikkeld om geconstateerde belemmeringen bij het bieden van palliatieve zorg aan te pakken en de organisatie en het leveren van persoonsgerichte **hoogwaardige palliatieve zorg voor iedereen** met een levensbedreigende ziekte of kwetsbaarheid en hun naasten te verbeteren, **om tot de dood te leven**. Haar acht essenties vormen een zorgpad dat kan dienen als een praktische richtlijn om beleidsmakers, managers en zorgverleners te helpen bij het integreren van palliatieve zorg en reguliere zorg.
Daarnaast zullen specifieke onderwijsprogrammema's de vaardigheden en competenties van alle zorgverleners moeten verbeteren en zal door samenwerking op alle institutionele niveaus een optimale continuïteit van hoogwaardige palliatieve zorg gewaarborgd moeten worden. Middels onderzoek dient bepaald te worden hoeveel specialisten in de palliatieve zorg nodig zijn om een geïntegreerd model voor palliatieve zorg in de Nederlandse gezondheidszorg te implementeren en te continueren.[1 18 45] Deze informatie stelt beleidsmakers in de gezondheidszorg en onderwijsinstellingen in staat om beschikbare middelen hierop af te stemmen.[46]
Om voorbereid te zijn op de verwachte toename van het aantal patiënten met levensbedreigende en levensbeperkende chronische ziekten en hun ziekte-gerelateerd lijden, moet de gezondheidszorg zich richten op de tijdige integratie van hoogwaardige palliatieve zorg in alle domeinen van de zorg.[4 6 17 47 48] **Dat moeten we** als samenleving **WILLEN!** in het belang van alle patiënten, hun families en de volksgezondheid.

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Curriculum Vitae

Manon Suze Anne Boddaert was born on September 10, 1964 in Woensdrecht. She attended Kennemer Lyceum in Overveen and obtained her Gymnasium diploma in 1982. That same year she travelled to the US as an exchange student and enrolled at North West Missouri State University in Maryville. In 1983 she started her medical studies at the VU University in Amsterdam and graduated cum laude in 1991. After this she went to work at the Department for Immunology & Haematology of the Wilhelmina Children's Hospital, subsequently trained to become a paediatrician at Leiden University medical centre (LUMC) and decided to change course in 1994. She worked in children-, youth- and adult psychiatry for RIAGG Flevoland until 1999 and continued her work providing psychosocial and palliative care to oncology patients at the Department of Medical Oncology at VU University medical centre (VUmc). In 2001 she started her training in palliative medicine at the University of Wales College of Medicine in Cardiff. She finished her Master's degree in 2005 with a thesis reporting her research of "Thalidomide in patients with cachexia due to advanced cancer" and became a member of the oncology staff at VUmc. She initiated a specialist palliative care team with her colleagues, developed palliative care residencies for general practitioners and elderly care physicians and started research projects concerning opioid-induced constipation and delirium. In 2010 she became medical director at Hospice Bardo in Hoofddorp, continued to provide palliative care residencies and, with her colleagues, initiated a specialist palliative care team and an outpatient clinic for palliative care within the Oncology Department of the Spaarne Gasthuis. These efforts resulted in a recognition as ESMO designated centre of integrated oncology & palliative care in 2013. At the end of the following year, she and a colleague were invited to work at the Netherlands Comprehensive Cancer organisation (IKNL) to support hospitals in setting up specialist palliative care teams. Within a year this grew into a whole-sector initiative to develop a national quality framework for palliative care, which was launched in 2017. Since then she has continued her work as a medical advisor for IKNL, combined it with similar activities for the Netherlands Association for Palliative care (PZNL) and, for one day a week, practices palliative medicine as a member of the specialist palliative care team in LUMC. She started her PhD research in 2019, outsourced by IKNL to the Centre of Expertise in Palliative Care of LUMC. During the COVID-19 pandemic she was involved in the development of several national guidelines as hands-on support for all healthcare professionals in providing palliative care and participated in the COVID-19 expert team of the Federation of Medical Specialists (FMS). She is currently a medical advisor to the second National Programme for Palliative Care (NPPZ II) focussed on the integration of the key elements of the Netherlands Quality Framework for Palliative Care into regular care

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