Quality palliative care for all - WANT IT! - towards death, while alive

Boddaert, M.S.A.

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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	**Bold** text: key elements of Netherlands Quality Framework for Palliative Care
▨ Functional integration	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., anderhalve-lijn 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!**

References

1. IKNL/Palliactief. Netherlands Quality Framework for Palliative Care. Utrecht 2017.
2. Dumanovsky T, Rogers M, Spragens LH, et al. Impact of Staffing on Access to Palliative Care in U.S. Hospitals. *J Palliat Med* 2015;18(12):998-9. doi: 10.1089/jpm.2015.0436 [published Online First: 2015/11/12]
3. Rogers M, Meier DE, Heitner R, et al. The National Palliative Care Registry: A Decade of Supporting Growth and Sustainability of Palliative Care Programmes. *J Palliat Med* 2019;22(9):1026-31. doi: 10.1089/jpm.2019.0262 [published Online First: 2019/07/23]
4. Hui D, Cherny N, Latino N, et al. The ‘critical mass’ survey of palliative care programme at ESMO designated centres of integrated oncology and palliative care. *Ann Oncol* 2017;28(9):2057-66. doi: 10.1093/annonc/mdx280 [published Online First: 2017/09/16]
5. Morin L, Onwuteaka-Philipsen BD. The promise of big data for palliative and end-of-life care research. *Palliat Med* 2021;35(9):1638-40. doi: 10.1177/02692163211048307 [published Online First: 2021/10/13]
6. De Schreye R, Smets T, Annemans L, et al. Applying Quality Indicators For Administrative Databases To Evaluate End-Of-Life Care For Cancer Patients In Belgium. *Health Aff (Millwood)* 2017;36(7):1234-43. doi: 10.1377/hlthaff.2017.0199 [published Online First: 2017/07/07]
7. Busse R. Diagnosis-related groups in Europe moving towards transparency, efficiency and quality in hospitals. Maidenhead, England: Open University Press 2011.
8. Abraha I, Serraino D, Montedori A, et al. Sensitivity and specificity of breast cancer ICD-9-CM codes in three Italian administrative healthcare databases: a diagnostic accuracy study. *BMJ Open* 2018;8(7):e020627. doi: 10.1136/bmjopen-2017-020627 [published Online First: 2018/07/25]
9. Cozzolino F, Bidoli E, Abraha I, et al. Accuracy of colorectal cancer ICD-9-CM codes in Italian administrative healthcare databases: a cross-sectional diagnostic study. *BMJ Open* 2018;8(7):e020630. doi: 10.1136/bmjopen-2017-020630 [published Online First: 2018/07/08]
10. Montedori A, Bidoli E, Serraino D, et al. Accuracy of lung cancer ICD-9-CM codes in Umbria, Napoli 3 Sud and Friuli Venezia Giulia administrative healthcare databases: a diagnostic accuracy study. *BMJ Open* 2018;8(5):e020628. doi: 10.1136/bmjopen-2017-020628 [published Online First: 2018/05/19]
11. Abraha I, Montedori A, Serraino D, et al. Accuracy of administrative databases in detecting primary breast cancer diagnoses: a systematic review. *BMJ Open* 2018;8(7):e019264. doi: 10.1136/bmjopen-2017-019264 [published Online First: 2018/07/25]
12. Hwang YJ, Park SM, Ahn S, et al. Diagnostic accuracy of administrative database for bile duct cancer by ICD-10 code in a tertiary institute in Korea. *Hepatobiliary Pancreat Dis Int* 2020;19(6):575-80. doi: 10.1016/j.hbpd.2020.03.002 [published Online First: 2020/04/07]
13. Sarkies MN, Bowles KA, Skinner EH, et al. Data collection methods in health services research: hospital length of stay and discharge destination. *Appl Clin Inform* 2015;6(1):96-109. doi: 10.4338/ACI-2014-10-RA-0097 [published Online First: 2015/04/08]

14. Benchimol EI, Manuel DG, To T, et al. Development and use of reporting guidelines for assessing the quality of validation studies of health administrative data. *J Clin Epidemiol* 2011;64(8):821-9. doi: 10.1016/j.jclinepi.2010.10.006 [published Online First: 2011/01/05]
15. De Schreye R, Houttekier D, Deliens L, et al. Developing indicators of appropriate and inappropriate end-of-life care in people with Alzheimer's disease, cancer or chronic obstructive pulmonary disease for population-level administrative databases: A RAND/UCLA appropriateness study. *Palliat Med* 2017;31(10):932-45. doi: 10.1177/0269216317705099 [published Online First: 2017/04/22]
16. Psaty BM, Koepsell TD, Lin D, et al. Assessment and control for confounding by indication in observational studies. *J Am Geriatr Soc* 1999;47(6):749-54. doi: 10.1111/j.1532-5415.1999.tb01603.x [published Online First: 1999/06/12]
17. Regieraad Kwaliteit van Zorg. Richtlijn voor richtlijnen (Guideline for guidelines). 2012.
18. Brouwers MC, Kho ME, Browman GP, et al. AGREE II: advancing guideline development, reporting and evaluation in health care. *CMAJ* 2010;182(18):E839-42. doi: 10.1503/cmaj.090449 [published Online First: 2010/07/07]
19. Junger S, Payne S, Brearley S, et al. Consensus building in palliative care: a Europe-wide delphi study on common understandings and conceptual differences. *J Pain Symptom Manage* 2012;44(2):192-205. doi: 10.1016/j.jpainsymman.2011.09.009 [published Online First: 2012/06/19]
20. World Health O. World report on aging and health. Geneva: World Health Organisation 2015.
21. Mathers CD, Stevens GA, Boerma T, et al. Causes of international increases in older age life expectancy. *Lancet* 2015;385(9967):540-8. doi: 10.1016/S0140-6736(14)60569-9 [published Online First: 2014/12/04]
22. Gomez-Batiste X, Martinez-Munoz M, Blay C, et al. Prevalence and characteristics of patients with advanced chronic conditions in need of palliative care in the general population: a cross-sectional study. *Palliat Med* 2014;28(4):302-11. doi: 10.1177/0269216313518266 [published Online First: 2014/01/10]
23. Sleeman KE, de Brito M, Etkind S, et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *Lancet Glob Health* 2019;7(7):e883-e92. doi: 10.1016/S2214-109X(19)30172-X [published Online First: 2019/05/28]
24. General Assembly of the United Nations (UN). Resolution 66/2. Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases 2011:5-6.
25. Quinn KL, Shurrab M, Gitau K, et al. Association of Receipt of Palliative Care Interventions With Health Care Use, Quality of Life, and Symptom Burden Among Adults With Chronic Noncancer Illness: A Systematic Review and Meta-analysis. *JAMA* 2020;324(14):1439-50. doi: 10.1001/jama.2020.14205 [published Online First: 2020/10/14]
26. Maetens A, Beernaert K, De Schreye R, et al. Impact of palliative home care support on the quality and costs of care at the end of life: a population-level matched cohort study. *BMJ Open* 2019;9(1):e025180. doi: 10.1136/bmjopen-2018-025180 [published Online First: 2019/01/24]

27. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010;363(8):733-42. doi: 10.1056/NEJMoa1000678 [published Online First: 2010/09/08]
28. Gaertner J, Siemens W, Meerpohl JJ, et al. Effect of specialist palliative care services on quality of life in adults with advanced incurable illness in hospital, hospice, or community settings: systematic review and meta-analysis. *BMJ* 2017;357:j2925. doi: 10.1136/bmj.j2925 [published Online First: 2017/07/06]
29. Haun MW, Estel S, Rucker G, et al. Early palliative care for adults with advanced cancer. *Cochrane Database Syst Rev* 2017;6:CD011129. doi: 10.1002/14651858.CD011129.pub2 [published Online First: 2017/06/13]
30. Vanbutsele G, Pardon K, Van Belle S, et al. Effect of early and systematic integration of palliative care in patients with advanced cancer: a randomised controlled trial. *Lancet Oncol* 2018;19(3):394-404. doi: 10.1016/S1470-2045(18)30060-3 [published Online First: 2018/02/07]
31. Kavalieratos D, Corbelli J, Zhang D, et al. Association Between Palliative Care and Patient and Caregiver Outcomes: A Systematic Review and Meta-analysis. *JAMA* 2016;316(20):2104-14. doi: 10.1001/jama.2016.16840 [published Online First: 2016/11/29]
32. Institute of Medicine, Committee on Approaching Death: Addressing Key End-of-Life Issues. Dying in America: improving quality and honoring individual preferences near the end of life,2015.
33. Ferrell BR, Temel JS, Temin S, et al. Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update. *J Clin Oncol* 2017;35(1):96-112. doi: 10.1200/JCO.2016.70.1474 [published Online First: 2016/12/31]
34. Jordan K, Aapro M, Kaasa S, et al. European Society for Medical Oncology (ESMO) position paper on supportive and palliative care. *Ann Oncol* 2018;29(1):36-43. doi: 10.1093/annonc/mdx757 [published Online First: 2017/12/19]
35. Boddaert MS, Pereira C, Adema J, et al. Inappropriate end-of-life cancer care in a generalist and specialist palliative care model: a nationwide retrospective population-based observational study. *BMJ Support Palliat Care* 2022;12(e1):e137-e45. doi: 10.1136/bmjspcare-2020-002302 [published Online First: 2020/12/24]
36. Boddaert M, Fransen H, Spierings L, et al. Association between inappropriate end-of-life cancer care and specialist palliative care: a retrospective observational study in two acute care hospitals. 2022
37. Brown CRL, Webber C, Seow HY, et al. Impact of physician-based palliative care delivery models on health care utilisation outcomes: A population-based retrospective cohort study. *Palliat Med* 2021;35(6):1170-80. doi: 10.1177/02692163211009440 [published Online First: 2021/04/23]
38. Ziegler LE, Craigs CL, West RM, et al. Is palliative care support associated with better quality end-of-life care indicators for patients with advanced cancer? A retrospective cohort study. *BMJ Open* 2018;8(1):e018284. doi: 10.1136/bmjopen-2017-018284 [published Online First: 2018/02/02]

39. Qureshi D, Tanuseputro P, Perez R, et al. Early initiation of palliative care is associated with reduced late-life acute-hospital use: A population-based retrospective cohort study. *Palliat Med* 2019;33(2):150-59. doi: 10.1177/0269216318815794 [published Online First: 2018/12/07]
40. Quinn KL, Stukel T, Stall NM, et al. Association between palliative care and healthcare outcomes among adults with terminal non-cancer illness: population based matched cohort study. *BMJ* 2020;370:m2257. doi: 10.1136/bmj.m2257 [published Online First: 2020/07/08]
41. Seow H, Sutradhar R, Burge F, et al. End-of-life outcomes with or without early palliative care: a propensity score matched, population-based cancer cohort study. *BMJ Open* 2021;11(2):e041432. doi: 10.1136/bmjopen-2020-041432 [published Online First: 2021/02/14]
42. Earp M, Cai P, Fong A, et al. Hospital-based acute care in the last 30 days of life among patients with chronic disease that received early, late or no specialist palliative care: a retrospective cohort study of eight chronic disease groups. *BMJ Open* 2021;11(3):e044196. doi: 10.1136/bmjopen-2020-044196 [published Online First: 2021/03/26]
43. Zhang B, Nilsson ME, Prigerson HG. Factors important to patients' quality of life at the end of life. *Arch Intern Med* 2012;172(15):1133-42. doi: 10.1001/archinternmed.2012.2364 [published Online First: 2012/07/11]
44. Bolt EE, Pasman HR, Willems D, et al. Appropriate and inappropriate care in the last phase of life: an explorative study among patients and relatives. *BMC Health Serv Res* 2016;16(1):655. doi: 10.1186/s12913-016-1879-3 [published Online First: 2016/11/17]
45. Wright AA, Zhang B, Ray A, et al. Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment. *JAMA* 2008;300(14):1665-73. doi: 10.1001/jama.300.14.1665
46. Tonnies J, Hartmann M, Jager D, et al. Aggressiveness of Care at the End-of-Life in Cancer Patients and Its Association With Psychosocial Functioning in Bereaved Caregivers. *Front Oncol* 2021;11:673147. doi: 10.3389/fonc.2021.673147 [published Online First: 2021/06/22]
47. Boddaert MS, Stoppelenburg A, Hasselaar J, et al. Specialist palliative care teams and characteristics related to referral rate: a national cross-sectional survey among hospitals in the Netherlands. *BMC Palliat Care* 2021;20(1):175. doi: 10.1186/s12904-021-00875-3 [published Online First: 2021/11/12]
48. 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. doi: 10.1186/s12913-016-1770-2 [published Online First: 2016/09/25]
49. Van Der Velden AW, De Heij AH, Van Den Beuken MH, et al. Identifying Dutch Hospitalised Patients with a Limited Life Expectancy and Palliative Care Team Involvement: A Flashmob Study. *Palliative Medicine* 2022;36:18.
50. Compton-Phillips A, Mohta NS. Care Redesign Survey: The Power of Palliative Care, 2019.
51. Henderson JD, Boyle A, Herx L, et al. Staffing a Specialist Palliative Care Service, a Team-Based Approach: Expert Consensus White Paper. *J Palliat Med* 2019;22(11):1318-23. doi: 10.1089/jpm.2019.0314 [published Online First: 2019/07/28]

52. Taghavi M, Johnston G, Urquhart R, et al. Workforce Planning for Community-Based Palliative Care Specialist Teams Using Operations Research. *J Pain Symptom Manage* 2020 doi: 10.1016/j.jpainsymman.2020.09.009 [published Online First: 2020/09/18]
53. Palliative Care Australia. Palliative Care Service Development Guidelines, 2018.
54. Boddaert MS, Douma J, Dijxhoorn AQ, et al. 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. *PLoS One* 2022;17(3):e0265726. doi: 10.1371/journal.pone.0265726 [published Online First: 2022/03/24]
55. Nevin M, Hynes G, Smith V. Healthcare providers' views and experiences of non-specialist palliative care in hospitals: A qualitative systematic review and thematic synthesis. *Palliat Med* 2020;34(5):605-18. doi: 10.1177/0269216319899335 [published Online First: 2020/02/06]
56. de Bruin J, Verhoef MJ, Slaets JPJ, et al. End-of-life care in the Dutch medical curricula. *Perspect Med Educ* 2018;7(5):325-31. doi: 10.1007/s40037-018-0447-4 [published Online First: 2018/09/07]
57. Pieters J, Dolmans D, Verstegen DML, et al. Palliative care education in the undergraduate medical curricula: students' views on the importance of, their confidence in, and knowledge of palliative care. *BMC Palliat Care* 2019;18(1):72. doi: 10.1186/s12904-019-0458-x [published Online First: 2019/08/29]
58. van der Steen JT, Radbruch L, Hertogh CM, et al. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* 2014;28(3):197-209. doi: 10.1177/0269216313493685 [published Online First: 2013/07/06]
59. Bolt SR, van der Steen JT, Schols J, et al. Nursing staff needs in providing palliative care for people with dementia at home or in long-term care facilities: A scoping review. *Int J Nurs Stud* 2019;96:143-52. doi: 10.1016/j.ijnurstu.2018.12.011 [published Online First: 2019/04/01]
60. Erel M, Marcus EL, Dekeyser-Ganz F. Barriers to palliative care for advanced dementia: a scoping review. *Ann Palliat Med* 2017;6(4):365-79. doi: 10.21037/apm.2017.06.13 [published Online First: 2017/07/30]
61. van der Stap L, de Nijs EJM, Oomes M, et al. The self-perceived palliative care barriers and educational needs of clinicians working in hospital primary care teams and referral patterns: lessons learned from a single-center survey and cohort study. *Ann Palliat Med* 2021;10(3):2620-37. doi: 10.21037/apm-20-1706 [published Online First: 2021/01/22]
62. van Riet Paap J, Vernooij-Dassen M, Brouwer F, et al. Improving the organisation of palliative care: identification of barriers and facilitators in five European countries. *Implement Sci* 2014;9:130. doi: 10.1186/s13012-014-0130-z [published Online First: 2015/02/17]
63. Virdun C, Luckett T, Davidson PM, et al. Strengthening palliative care in the hospital setting: a codesign study. *BMJ Support Palliat Care* 2020 doi: 10.1136/bmjspcare-2020-002645 [published Online First: 2020/10/30]

64. Teunissen SC, Wesker W, Kruitwagen C, et al. Symptom prevalence in patients with incurable cancer: a systematic review. *J Pain Symptom Manage* 2007;34(1):94-104. doi: 10.1016/j.jpainsymman.2006.10.015 [published Online First: 2007/05/19]
65. Vissers KC, van den Brand MW, Jacobs J, et al. Palliative medicine update: a multidisciplinary approach. *Pain Pract* 2013;13(7):576-88. doi: 10.1111/papr.12025 [published Online First: 2012/12/18]
66. Webber C, Isenberg SR, Scott M, et al. Inpatient Palliative Care Is Associated with the Receipt of Palliative Care in the Community after Hospital Discharge: A Retrospective Cohort Study. *J Palliat Med* 2022 doi: 10.1089/jpm.2021.0496 [published Online First: 2022/01/11]
67. Flierman I, van Seben R, van Rijn M, et al. Health Care Providers' Views on the Transition Between Hospital and Primary Care in Patients in the Palliative Phase: A Qualitative Description Study. *J Pain Symptom Manage* 2020;60(2):372-80 e1. doi: 10.1016/j.jpainsymman.2020.02.018 [published Online First: 2020/03/07]
68. Flierman I, Nugteren IC, van Seben R, et al. How do hospital-based nurses and physicians identify the palliative phase in their patients and what difficulties exist? A qualitative interview study. *BMC Palliat Care* 2019;18(1):54. doi: 10.1186/s12904-019-0439-0 [published Online First: 2019/07/11]
69. Thoonsen B, Vissers K, Verhagen S, et al. Training general practitioners in early identification and anticipatory palliative care planning: a randomised controlled trial. *BMC Fam Pract* 2015;16:126. doi: 10.1186/s12875-015-0342-6 [published Online First: 2015/09/24]
70. Thoonsen B, Gerritzen SHM, Vissers KCP, et al. Training general practitioners contributes to the identification of palliative patients and to multidimensional care provision: secondary outcomes of an RCT. *BMJ Support Palliat Care* 2019;9(1):e18. doi: 10.1136/bmjspcare-2015-001031 [published Online First: 2016/04/20]
71. Optimaliseren Onderwijs Palliatieve Zorg (O2PZ). Onderwijsraamwerk palliatieve zorg (Education framework for Palliative Care) 2.0. Amsterdam, 2020.
72. Koper I, Pasman HRW, Van der Plas AGM, et al. The association between PaTz and improved palliative care in the primary care setting: a cross-sectional survey. *BMC Fam Pract* 2019;20(1):112. doi: 10.1186/s12875-019-1002-z [published Online First: 2019/08/05]
73. van der Plas AG, Hagens M, Pasman HR, et al. PaTz groups for primary palliative care: reinventing cooperation between general practitioners and district nurses in palliative care: an evaluation study combining data from focus groups and a questionnaire. *BMC Fam Pract* 2014;15:14. doi: 10.1186/1471-2296-15-14 [published Online First: 2014/01/22]
74. van der Plas AG, Pasman HRW, Schweitzer B, et al. Improving palliative care provision in primary care: a pre- and post-survey evaluation among PaTz groups. *Br J Gen Pract* 2018;68(670):e351-e59. doi: 10.3399/bjgp18X695753 [published Online First: 2018/03/28]
75. Engel M, Stoppelenburg A, van der Ark A, et al. Development and implementation of a transmural palliative care consultation service: a multiple case study in the Netherlands. *BMC Palliat Care* 2021;20(1):81. doi: 10.1186/s12904-021-00767-6 [published Online First: 2021/06/07]

76. IKNL/Palliactief. Knelpuntenanalyse Palliatieve Zorg in de eerste lijn (Bottleneck analysis of primary palliative care). Utrecht, 2017:22-33.
77. IKNL/Palliactief. Palliatieve Zorg in Nederlandse ziekenhuizen (Palliative care in Dutch hospitals). Utrecht, 2015.
78. Steering Committee for Appropriate End-of-Life Care. Just because we can, doesn't mean we should. Utrecht: Royal Dutch Medical Association, 2015.
79. Nederlandse Zorgautoriteit (NZa). Samenwerken in de palliatieve zorg (Collaborating in palliative care), 2018.
80. Nederlandse Zorgautoriteit (NZa). Visie bekostiging palliatieve zorg (Perspective on funding of palliative care). 2022
81. PZNL/IKNL. Kerncijfers Palliatieve Zorg, 2019.
82. Bennardi M, Diviani N, Gamondi C, et al. Palliative care utilisation in oncology and hemato-oncology: a systematic review of cognitive barriers and facilitators from the perspective of healthcare professionals, adult patients, and their families. *BMC Palliat Care* 2020;19(1):47. doi: 10.1186/s12904-020-00556-7 [published Online First: 2020/04/15]
83. Dalgaard KM, Bergenholtz H, Nielsen ME, et al. Early integration of palliative care in hospitals: A systematic review on methods, barriers, and outcome. *Palliat Support Care* 2014;12(6):495-513. doi: 10.1017/S1478951513001338 [published Online First: 2014/03/14]
84. White N, Kupeli N, Vickerstaff V, et al. How accurate is the 'Surprise Question' at identifying patients at the end of life? A systematic review and meta-analysis. *BMC Med* 2017;15(1):139. doi: 10.1186/s12916-017-0907-4 [published Online First: 2017/08/03]
85. Verhoef MJ, de Nijs EJM, Fiocco M, et al. Surprise Question and Performance Status Indicate Urgency of Palliative Care Needs in Patients with Advanced Cancer at the Emergency Department: An Observational Cohort Study. *J Palliat Med* 2020;23(6):801-08. doi: 10.1089/jpm.2019.0413 [published Online First: 2019/12/28]
86. van Wijmen MPS, Schweitzer BPM, Pasman HR, et al. Identifying patients who could benefit from palliative care by making use of the general practice information system: the Surprise Question versus the SPICT. *Family Practice* 2020;37(5):641-47. doi: 10.1093/fampra/cmaa049
87. Verhoef M-J, de Nijs E, Horeweg N, et al. Palliative care needs of advanced cancer patients in the emergency department at the end of life: an observational cohort study. *Supportive Care in Cancer* 2020;28(3):1097-107. doi: 10.1007/s00520-019-04906-x
88. Heitner R, Rogers M, Silvers A, et al. Palliative Care Team Perceptions of Standardised Palliative Care Referral Criteria Implementation in Hospital Settings. *J Palliat Med* 2020 doi: 10.1089/jpm.2020.0296 [published Online First: 2020/12/19]
89. Hui D, Mori M, Watanabe SM, et al. Referral criteria for outpatient specialty palliative cancer care: an international consensus. *Lancet Oncol* 2016;17(12):e552-e59. doi: 10.1016/s1470-2045(16)30577-0 [published Online First: 2016/12/08]
90. Davis MP, Strasser F, Cherny N. How well is palliative care integrated into cancer care? A MASCC, ESMO, and EAPC Project. *Support Care Cancer* 2015;23(9):2677-85. doi: 10.1007/s00520-015-

2630-z [published Online First: 2015/02/14]

91. Centeno C, Bolognesi D, Biasco G. Comparative analysis of specialisation in palliative medicine processes within the World Health Organisation European region. *J Pain Symptom Manage* 2015;49(5):861-70. doi: 10.1016/j.jpainsymman.2014.10.019 [published Online First: 2015/01/28]
92. Raad Volksgezondheid & Samenleving. Stervelingen - Beter samenleven met de dood, 2021.
93. Raad Volksgezondheid & Samenleving. Leven met het einde in zicht - de waarde van een brede benadering. Den Haag, 2022.
94. Janssen DJA, Johnson MJ, Spruit MA. Palliative care needs assessment in chronic heart failure. *Curr Opin Support Palliat Care* 2018;12(1):25-31. doi: 10.1097/SPC.0000000000000317 [published Online First: 2017/12/06]
95. Ament SMC, van den Beuken-Everdingen M, Maessen JMC, et al. Professionals guidance about palliative medicine in chronic heart failure: a mixed-method study. *BMJ Support Palliat Care* 2020 doi: 10.1136/bmjspcare-2020-002580 [published Online First: 2020/11/28]
96. Broese JMC, van der Kleij R, Kerstjens HAM, et al. A cluster randomised controlled trial on a multifaceted implementation strategy to promote integrated palliative care in COPD: study protocol of the COMPASSION study. *BMC Palliat Care* 2020;19(1):155. doi: 10.1186/s12904-020-00657-3 [published Online First: 2020/10/12]
97. Quill TE, Abernethy AP. Generalist plus specialist palliative care--creating a more sustainable model. *N Engl J Med* 2013;368(13):1173-5. doi: 10.1056/NEJMp1215620 [published Online First: 2013/03/08]
98. van der Velden A, Engels Y, Nanninga M, et al. What Matters Most for the Dutch Public in Palliative Care: A Survey. *Journal of Pain and Symptom Management* 2018;56(6):e107. doi: 10.1016/j.jpainsymman.2018.10.358
99. The Choice in End-of-life care Programme Board. What's important to me. 2015.
100. Virdun C, Luckett T, Lorenz K, et al. Dying in the hospital setting: A meta-synthesis identifying the elements of end-of-life care that patients and their families describe as being important. *Palliat Med* 2017;31(7):587-601. doi: 10.1177/0269216316673547 [published Online First: 2016/12/10]
101. Oosterveld-Vlug MG, Custers B, Hofstede J, et al. What are essential elements of high-quality palliative care at home? An interview study among patients and relatives faced with advanced cancer. *BMC Palliat Care* 2019;18(1):96. doi: 10.1186/s12904-019-0485-7 [published Online First: 2019/11/07]
102. Chen AY, Chen B, Kuo CC. Better continuity of care improves the quality of end-of-life care among elderly patients with end-stage renal disease. *Sci Rep* 2020;10(1):19716. doi: 10.1038/s41598-020-76707-w [published Online First: 2020/11/14]
103. Virdun C, Luckett T, Davidson PM, et al. Dying in the hospital setting: A systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. *Palliat Med* 2015;29(9):774-96. doi: 10.1177/0269216315583032 [published Online First: 2015/04/30]
104. Kaasa S, Loge JH, Aapro M, et al. Integration of oncology and palliative care: a Lancet Oncology

Commission. *Lancet Oncol* 2018;19(11):e588-e653. doi: 10.1016/S1470-2045(18)30415-7 [published Online First: 2018/10/23]

105. Ahluwalia SC, Chen C, Raaen L, et al. A Systematic Review in Support of the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care, Fourth Edition. *J Pain Symptom Manage* 2018;56(6):831-70. doi: 10.1016/j.jpainsymman.2018.09.008 [published Online First: 2018/11/06]
106. Dijxhoorn AQ, Brom L, van der Linden YM, et al. Healthcare Professionals' Work-Related Stress in Palliative Care: A Cross-Sectional Survey. *J Pain Symptom Manage* 2021 doi: 10.1016/j.jpainsymman.2021.04.004 [published Online First: 2021/04/18]
107. IKNL/PZNL. Resultaten project TAPA$, TrAnsmurale PAlliative zorg met passende beko$tiging. (Transmural palliative care with appropriate reimbursement), 2022.
108. PZNL. Transmurale palliatieve zorg: hulpmiddel bij implementatie kwaliteitskader? Methodiek veldverkenning., 2018.
109. Chantal F R Pereira, Anne-Floor Q Dijxhoorn, Berdine Koekoek, et al. Potentially inappropriate end-of-life care and healthcare costs in the last 30 days of life in regions providing integrated palliative care in the Netherlands: a registration-based study. *(submitted)*
110. Porter ME, Lee TH. The strategy that will fix health care. *Harvard Business Review* 2013;10.
111. Zorginstituut Nederland (ZiN), Nederlandse Zorgautoriteit (NZa). Samenwerken aan passende zorg: de toekomst is nú. (Cooperating for appropriate care: the future is now.), 2020.
112. Gemmel P, al. e. Constructing and Modeling future PAlliative care Service organisation (Een COMPAS voor de organisatie van geïntegreerde palliatieve zorg in de toekomst). Gent, 2021.
113. Hasselaar JCACCPS. Integrated Palliative Care: Clinical, Organisational, and Health System Perspectives. 2019
114. Valentijn PP, Schepman SM, Opheij W, et al. Understanding integrated care: a comprehensive conceptual framework based on the integrative functions of primary care. *Int J Integr Care* 2013;13:e010. doi: 10.5334/ijic.886 [published Online First: 2013/05/21]
115. van der Baan FH, Koldenhof JJ, de Nijs EJ, et al. Validation of the Dutch version of the Edmonton Symptom Assessment System. *Cancer Med* 2020;9(17):6111-21. doi: 10.1002/cam4.3253 [published Online First: 2020/07/10]
116. de Vries S, Lormans T, de Graaf E, et al. The Content Validity of the Items Related to the Social and Spiritual Dimensions of the Utrecht Symptom Diary-4 Dimensional From a Patient's Perspective: A Qualitative Study. *J Pain Symptom Manage* 2021;61(2):287-94 e2. doi: 10.1016/j.jpainsymman.2020.07.036 [published Online First: 2020/08/11]
117. World Health Assembly. Strengthening of palliative care as a component of integrated treatment throughout the life course: Report by the Secretariat. 2014.
118. Europe Co, Committee on Social Affairs Health and Sustainable Development. The provision of palliative care in Europe.
119. Meier DE, Back AL, Berman A, et al. A National Strategy For Palliative Care. *Health Aff (Millwood)* 2017;36(7):1265-73. doi: 10.1377/hlthaff.2017.0164 [published Online First: 2017/07/07]

120. Kayastha N, LeBlanc TW. Why Are We Failing to Do What Works? Musings on Outpatient Palliative Care Integration in Cancer Care. *JCO Oncol Pract* 2022;18(4):255-57. doi: 10.1200/OP.21.00794 [published Online First: 2021/12/23]

121. Dutch Federation of Oncological Societies, SONCOS. Standardisation of Multidisciplinary Cancer Care in the Netherlands. Utrecht, 2017.

122. Hui D, Bansal S, Strasser F, et al. Indicators of integration of oncology and palliative care programmes: an international consensus. *Ann Oncol* 2015;26(9):1953-59. doi: 10.1093/annonc/mdv269 [published Online First: 2015/06/20]

123. Klapwijk MS, Dekker NL, Caljouw MAA, et al. Experiences with the Liverpool care pathway for the dying patient in nursing home residents: a mixed-method study to assess physicians' and nurse practitioners' perceptions. *BMC Palliat Care* 2020;19(1):183. doi: 10.1186/s12904-020-00686-y [published Online First: 2020/12/02]

124. Grunfeld E, Urquhart R, Mykhalovskiy E, et al. Toward population-based indicators of quality end-of-life care: testing stakeholder agreement. *Cancer* 2008;112(10):2301-8. doi: 10.1002/cncr.23428 [published Online First: 2008/03/26]

125. Hui D, Hannon BL, Zimmermann C, et al. Improving patient and caregiver outcomes in oncology: Team-based, timely, and targeted palliative care. *CA Cancer J Clin* 2018;68(5):356-76. doi: 10.3322/caac.21490 [published Online First: 2018/10/03]

126. Mitchell S, Tan A, Moine S, et al. Primary palliative care needs urgent attention. *BMJ* 2019;365:l1827. doi: 10.1136/bmj.l1827 [published Online First: 2019/04/20]

127. Beernaert K, Deliens L, Pardon K, et al. What Are Physicians' Reasons for Not Referring People with Life-Limiting Illnesses to Specialist Palliative Care Services? A Nationwide Survey. *PLoS One* 2015;10(9):e0137251. doi: 10.1371/journal.pone.0137251 [published Online First: 2015/09/12]