Timely integration of palliative care into oncology

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COLOPHON

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Table of contents

CHAPTER 1

General introduction

The global incidence of cancer is on the rise. In 2020, there were an estimated 20 million new diagnoses worldwide. This number is predicted to increase by 77%, amounting to 35 million new cancer cases worldwide by 2050 [1]. The prevalence of metastatic cancer is also increasing with a projected 700,000 people living with metastatic breast, prostate, lung, colorectal, bladder cancer, or metastatic melanoma in the United States [2]. In the Netherlands, the number of new cancer cases in 2023 was 128,927, representing a prevalence of 7.5% in a population of 17.33 million [3]. Concurrently, the number of patients with metastatic cancer is also rising. In the Netherlands, one in five patients has metastatic cancer at diagnosis and approximately 25,000 people are newly diagnosed with metastatic cancer each year. An estimated 17,000 patients develop metastases after their initial diagnosis of non-metastatic cancer [4, 5]. In 2022, cancer was responsible for nearly 10 million deaths worldwide making it one of the leading causes of death [6].

Improvements in a wide array of treatment options, such as in local radiotherapy treatment, surgery and systemic treatments with novel treatment options, including targeted therapy and immunotherapy, have changed the disease trajectory of patients with incurable solid cancers. For a specific group of patients, depending on the subtype of the disease, this has resulted in no evidence of disease or even complete remission [7-11]. For other patients, improved and novel therapies have caused a significant temporary improvement of their condition, or even a long term ongoing response, resulting in patients living longer with a reasonably good quality of life [12]. This increase in survival has been particularly significant for certain types of cancer, such as melanoma, non-small cell lung cancer, and colorectal cancer [13-16].

Despite these advances for some subgroups of patients, the overall median survival for patients with metastatic cancer at primary diagnosis increased by just over one month between the periods 2008-2012 and 2018-2022. The increase was greatest for metastatic prostate and breast cancer at over 15 and 11 months respectively, while there was no improvement in median survival for bladder cancer [5, 17, 18]. During the period 2018-2022, the median survival for patients with metastatic cancer at primary diagnosis was 7 months, with considerable differences between age groups (ranging from 12 months for patients aged 18-64 to less than four months for patients over 75 years) [18]. A similar median survival was found in a study with data from the American National Cancer

Institute's Surveillance, Epidemiology, and End Results, which showed a median survival of ten months for patients diagnosed with metastatic cancer [19].

Having incurable cancer is a heavy burden; two-thirds of newly diagnosed patients with incurable cancer deal with significant distress and patients report unmet needs and symptoms across all four domains (physical, psychological, social and spiritual), of which some can be attributed to the effects of the cancer treatment [20-22]. Novel treatment options cause new side-effects, including immune-related adverse events among patients undergoing immunotherapy [23-26].

Palliative care and the benefits of timely integration into oncology

Cancer has been projected to be one of the main diseases responsible for the growth in palliative care needs, due to the expected increase in the incidence of incurable cancer and the prevalence of pain and high symptom burden [27]. Another factor that drives the increase in palliative care needs is the extended life expectancy of subgroups of patients with incurable cancer due to immunotherapy and targeted therapies [12].

Palliative care is defined by the WHO as an approach that improves the quality of life of patients and their families facing a life-threatening illness, by preventing and relieving suffering through early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems [28]. A substantial body of literature has demonstrated the benefits of timely integration of palliative care for patients with incurable cancer and their families. It improves patients' quality of life, satisfaction with care, symptom burden, overall survival, decreases caregivers' depressive symptoms, reduces the chance of potential inappropriate end-of-life care and it may even reduce overall healthcare costs [29-37]. These benefits call for an integrated care model, in which palliative care is integrated into standard oncology care in a timely manner.

There are several factors that facilitate the timely integration of palliative care into standard oncology care, including the implementation of clinical care pathways [38], referral guidelines [39], training of clinicians, and the availability of resources and infrastructure. Another element for advancing this integration is the development of guidelines. Guidelines help clinicians working in oncology with decision making and are imperative for improving the quality of cancer care [40, 41]. Over the last decade, a great body of literature emphasising the importance of timely integration of palliative care has resulted in the development of international guidelines, recommendations, criteria and statements, issued by the European Society for Medical Oncology (ESMO) [42, 43], the American Society of Clinical Oncology (ASCO) [44] and the Lancet Oncology Commission [38].

There are several conceptual models for the integration of palliative care into oncology care, including the needs-based model and the time-based model [38, 45]. In the needs-based model, patients and their relatives are categorised based on the complexity of their needs. The primary care team can attend to most needs, while palliative care specialists can attend to more complex care needs. In the time-based model, palliative care is introduced at diagnosis and increases over time as patients' palliative care needs increase (Figure 1). This model emphasises the timing and extent of palliative care involvement during the disease trajectory. Both models require an integrated care approach in which the tumour-directed approach (focussing on treating the disease) and the host-directed approach (focussing on the patient with the disease and on quality of life) are combined [38, 46].

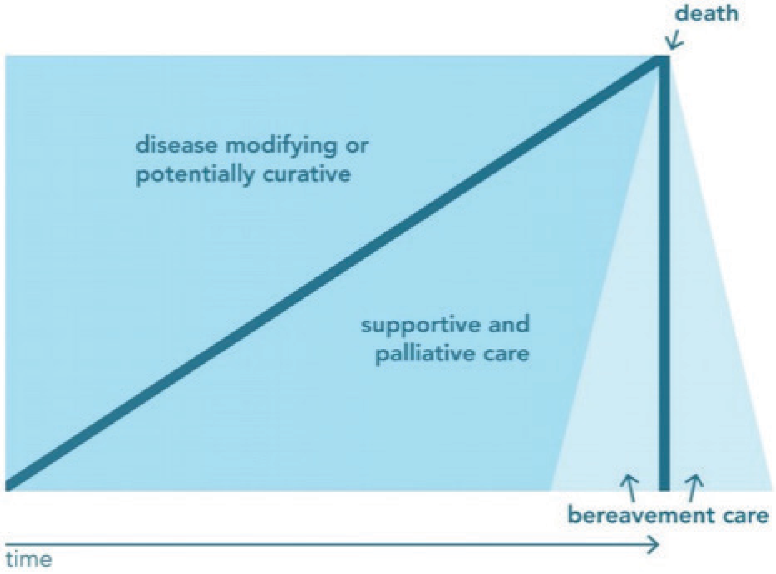
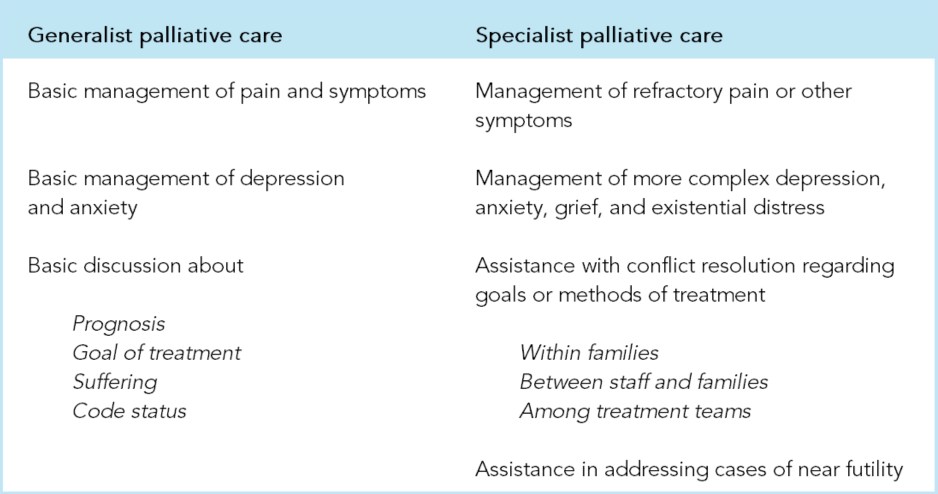


Figure 1 The time-based model, adapted from Lynn and Adamson 2003

Current practice in the Netherlands

In the Netherlands, a generalist-specialist model is applied to provide palliative care. In this model, every health care professional is considered a palliative care generalist and provides palliative care based on their standard medical training. This includes basic symptom assessment and management across the four dimensions (physical, psychological, social and spiritual) and basic discussions regarding care wishes. Palliative care specialists are clinicians who are additionally trained in palliative care and are often organised in a Specialist Palliative Care Team (SPCT). PC consultants of the SPCT can assist in managing more complex symptoms or with conflict resolutions regarding goals or treatment (Table 1). An underlying assumption of this model is that the SPCT and palliative care generalists collaborate in caring for patients, and do not operate in separate silos. The SPCT can be seen as an additional layer of care that can be added in case of complex care needs (Figure 2) [47-49].

Table 1 Skillsets for generalist and specialist palliative care providers, adapted from Quill et al. [47]



Generalist palliative care	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 discussion about *Prognosis* *Goal 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

Since 2017, every Dutch hospital caring for patients with cancer is obliged to have a multidisciplinary SPCT. This requirement set by the standardisation report for oncology care by the platform Oncology – SONCOS, to which every hospital providing oncology care has to adhere [50]. The palliative care specialists of the SPCT, also referred to as PC consultants, can support palliative care generalists through peer-to-peer consultation, or by accepting patients and their families for a consultation. The SONCOS standardisation report also includes several requirements regarding the SPCT, such as which clinicians should be included in the SPCT, the education level of members of the team, and which clinicians should be available for consultation.

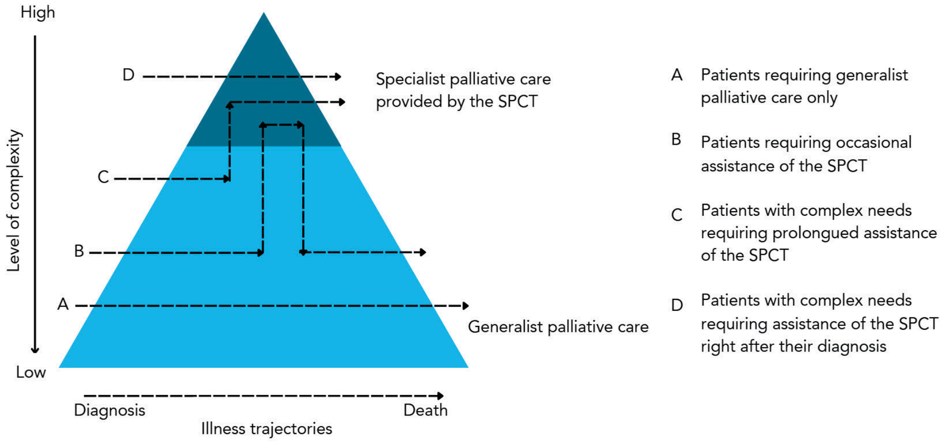


Figure 2 Collaboration between the SPCT and palliative care generalists, adapted from LEAP Core, Palladium Canada [49]

To gain more insight into the development of the SPCTs in the Netherlands, every three years all SPCTs receive a questionnaire. With the outcomes the current practice of specialist palliative care is monitored and assessed [51-53]. The most recent results showed that the coverage ratio of SPCTs was 1.7% in 2023, meaning that 1.7% of all admitted patients were seen by a palliative care consultant from the SPCT. International guidelines and studies have suggested that hospital referral rates to the SPCT may approximate 3-4% [54-57]. A national single-centre survey and cohort study found that 26% of patients were referred more than three months before death, 37% were referred between the last three months to two weeks before death and 37% of patients were referred in the dying phase (less than two weeks before death) [58]. These studies show that the number of referrals to the SPCT in the Netherlands is low and referrals occur late in patients' disease trajectory.

Barriers for timely integration of PC in a generalist-specialist model

Barriers for the integration of palliative care into oncology exist on various domains: the domain of clinicians, patients, organisations and societal/policy [59]. On the level of clinicians, known barriers include a focus on the physician domain and on cancer treatment, not wanting to cause a loss of hope, and a lack of awareness of patients' symptoms or palliative care needs [59-63]. Numerous tools exist for identifying patients' potential palliative care needs, such as the Surprise Question (SQ) [64], the Supportive and Palliative Care Indicators Tool (SPICT) [65] and the Radboud Indicators for Palliative Care Needs (RADPAC) [66]. However, these tools are not always systematically implemented in clinical care pathways or daily clinical practice. On the domain of both clinicians and patients, a known barrier includes the tendency to overestimate patients' prognoses and survival [67-69], potentially resulting in delayed or omitted conversations about care wishes [38]. Moreover, not all patients know what palliative care entails and many associate it with end-of-life care [60, 62]. On the organisational domain barriers include a lack of time, but also include the reimbursement policies within hospitals that are mostly aimed at prescribing anticancer treatments [70, 71]. Last, barriers on the societal/policy domain include misconceptions and negative stereotypes about palliative care, the lack of education and training and the absence of guidelines on the timely integration of generalist and specialist palliative care [59, 60, 62, 63].

Aim and outline of this thesis

The overall aim of this thesis is to contribute to the timely integration of palliative care into oncology care.

The general aims were:

1. To achieve consensus among clinicians, patients with incurable cancer and relative representatives about essential elements of timely integration of palliative care into oncology care
2. To explore how oncology clinicians and patients with incurable cancer perceive 'timely palliative care' and how it is delivered in a generalist-specialist model
3. To develop recommendations on timely integration of palliative care into oncology hospital care in the Netherlands
4. To assess the feasibility of the recommendations on timely integration of palliative care into oncology hospital care in four Dutch hospitals
5. To assess the provision of key components of palliative care in the

Netherlands

Chapter 2 describes the results of a national Delphi study among oncology clinicians, patients with incurable cancer and family representatives in which elements of timely integration of palliative care into hospital oncology care were identified (aim 1). Since there is no clear definition of what timely palliative care in a generalist-specialist model entails, **chapter 3** elaborates on how oncology clinicians and patients with incurable cancer perceive 'timely palliative care' and how it is delivered in daily clinical practice (aim 2). Compared to solid cancers, the integration of palliative care for patients with haematological malignancies lags behind. **Chapter 4** describes the perspectives and experiences of haematological clinicians regarding palliative care, their perceived barriers and facilitators (aim 2). **Chapter 5** shows the results of a pilot study, in which the feasibility of the three recommendations on the timely integration of palliative care into oncology hospital care was assessed (aim 4). **Chapter 6** describes the provision of key components of palliative care, specifically advance care planning and routine symptom monitoring, in everyday practice in Dutch hospitals, based on data from a cross-sectional national survey of SPCTs in Dutch hospitals (aim 5).

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CHAPTER 2

Characteristics of timely integration of palliative care into oncology hospital care for patients with incurable cancer: results of a Delphi Study

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Abstract

Purpose To identify elements of timely integration of palliative care (PC) into hospital oncology care from best practices. Thereafter, to assess the level of consensus among oncology and PC specialists and patient- and relative representatives on the characteristics of timely integration of PC.

Methods A three-round modified Delphi study was conducted. The expert panel consisted of 83 healthcare professionals (HCPs) from 21 Dutch hospitals (43 physicians, 40 nurses), 6 patient- and 2 relative representatives. In the first round, four elements of integrated PC were considered: (1) identification of potential PC needs (2), advance care planning (ACP), (3) routine symptom monitoring and (4) involvement of the specialist palliative care team (SPCT). In subsequent rounds, the panellists assessed which characteristics were triggers for initiating an element. A priori consensus was set at ≥70%.

Results A total of 71 (78%) panellists completed the first questionnaire, 65 (71%) the second, and 49 (54%) the third. Panellists agreed that all patients with incurable cancer should have their PC needs assessed (97%), symptoms monitored (91%) and ACP initiated (86%). The SPCT should be involved at the patient’s request (86%) or when patients suffer from increased symptom burden on multiple dimensions (76%). Patients with a life expectancy of less than 3 months should be offered a consultation (71%).

Conclusion The expert panel agreed that timely integration of PC into oncology is important for all patients with incurable cancer, using early identification, ACP and routine symptom monitoring. Involvement of the SPCT is particularly needed in patients with multidimensional symptom burden and in those nearing death.

Introduction

Despite advances in diagnostics and treatment options, cancer remains one of the leading causes of premature death [1]. It is predicted that cancer will cause 11,5 million deaths worldwide in 2030 [2]. This implies that the number of people with palliative care (PC) needs will also increase, with cancer being one of the main drivers [3]. A growing body of literature demonstrates the positive effects of timely integration of PC in the cancer trajectory, including improved quality of life, reduced depressive feelings and symptom burden, increased satisfaction with care, and even improved survival rates [4-7]. This recognition of PC as an integral aspect of oncology care has prompted research into indicators of integration of PC and oncology programs for patients with advanced cancer. In a previous study, 47 physicians specialised in both oncology and PC reached consensus on thirteen indicators of integration, including the presence of interdisciplinary PC teams, routine symptom monitoring and routine documentation of advance care plans [8]. The Lancet Oncology Commission has identified different models of integration of PC into oncology, including the use of standardised care pathways, systematic assessment, multidisciplinary teams and an interdisciplinary approach [9].

In the Netherlands a mixed generalist-specialist PC model is used, which means that all HCPs caring for patients with a life-limiting illness are considered PC generalists and provide PC as part of usual care. They are supported by PC specialists when needed. Specialised PC in hospitals is organised in specialist palliative care consultation teams (SPCTs). A SPCT advises HCPs on individual cases and provides a variety of educational activities. Patients and families can also be referred to the team for consultation. A large nationwide study in the Netherlands has shown that improving the access to a SPCT for patients with cancer can reduce the number of patients receiving potentially inappropriate end-of-life care [10].

However, there are no official (inter)national guidelines for the timely integration of PC into hospital oncology care for patients with incurable cancer. Most hospitals focus on different elements of timely integrated care, such as developing standardised integrated pathways [11, 12], using an online symptom-monitoring and management tool [13] or researching prognostic instruments such as the Surprise Question [14], leading to a wide variation in clinical practice. Therefore, the aim of this study was to identify elements of timely integration of PC in oncological hospital care in the Netherlands and to achieve consensus among oncology- and PC specialists on the essential characteristics of these identified elements, using the following research questions: 1) How do hospitals with oncology care embed different elements of timely integration of PC in their daily clinical practice? 2) What characteristics of these elements are considered essential for timely integration?

Methods

Study Design

A modified three-round Delphi study was conducted to reach consensus on the essential characteristics of timely integration of PC in oncology. This Delphi study followed the process as used to reach consensus on concepts in the field of PC [15] (Figure 1). The Guidance on Conducting and Reporting Delphi Studies (CREDES) checklist was used for reporting [16].

Panellists

The expert panel consisted of 83 HCPs (physicians and nurses), 6 patient- and 2 relative representatives. HCPs were recruited on the basis of their expertise in either oncology or PC. The objective was to recruit at least two HCPs (one physician and one nurse) who were specialists in oncology but had no further specialist training in PC, and one PC specialist (either physician or nurse) per hospital. Attention was paid to include various oncologists (e.g. medical oncologists, radiation oncologists, oncological surgeons). To ensure the involvement of medical associations, six of the HCPs were representatives of the Dutch medical associations related to oncology: Dutch Association of Medical Oncologist (NVMO), Dutch Association of Radiotherapist in Oncology (NVRO), Dutch Association of Oncological Surgery (NVvH) and Dutch Nursing Society (V&VN).

The HCPs were recruited by the regional advisors of the Dutch palliative care consortia. The Netherlands is divided into seven palliative care consortia. These are networks and partnerships of different national- and regional organisations that focus on improving and implementing PC. The advisors of the consortia were asked to contact three hospitals in their region (one academic and two non-academic) that they considered having good practice in the timely integration of PC. The patient- and relative representatives were recruited through the Dutch Federation of Cancer Patients organisations (NFK).

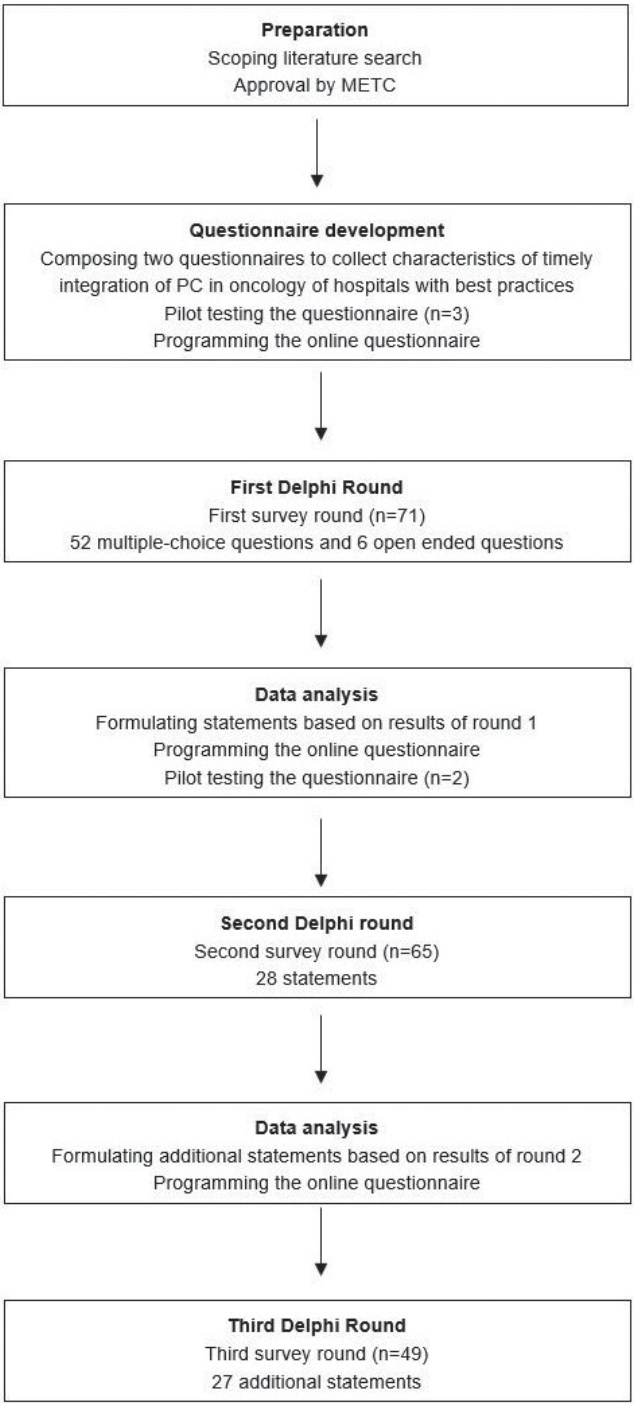

Figure 1 Flowchart of the stages of Delphi process

Process of development of questionnaire

Based on key papers in this area of research, such as Kaasa et al. [9], Hui et al. [8] and the domains of PC as defined in the Netherlands Quality Framework for Palliative Care [17], four elements were identified as essential for the timely integration of PC into oncology care: 1) identification of potential PC needs, 2) advance care planning, 3) routine symptom monitoring and 4) involvement of the specialist palliative care team. Identification of palliative care needs was defined as the recognition of patients with a life-threatening illness or frailty with problematic questions and/or needs in physical, social, psychological and/or spiritual areas.

Delphi round 1

The first Delphi round was conducted between October and November 2021. The aim of this round was to identify how HCPs embed the four elements into their daily clinical practice. For each element three characteristics were collected: 1) for whom (for which patient groups the element is initiated), 2) when (when in the disease trajectory the element is initiated), and 3) by whom (which clinician is responsible for initiating the element). Two versions of the questionnaire were drafted; one for HCPs and one for the patient- and relative representatives. HCPs were asked about their own clinical practice and the general practice in their hospital. Patient- and relative representatives were asked about their personal experience with (timely) PC and what, according to them, timely PC should look like in general for patients with incurable cancer. The questionnaires were pilot tested using the think aloud method (n=3). The questions included an open-ended text box where panellists could add response categories that were not opted in the multiple choice categories. Panellists were able to select multiple answer categories.

Delphi round 2

The second round was conducted in January 2022. The results of the first round (Table 2) were analysed and the three to five most selected characteristics per element were used to formulate statements. The response format was a 5-point Likert scale. HCPs and patient- and relative representatives received the same questionnaire.

Delphi round 3

The third round was conducted in April 2022 and included 27 additional statements with a 5-point Likert scale as response format. Again HCPs and patient- and relative representatives received the same questionnaire.

Data collection

The online questionnaire was sent by email and panellists were asked to complete the questionnaire within two weeks. After two weeks a friendly reminder was sent and two weeks after the reminder the questionnaire was closed. Each survey round took approximately four weeks to complete. To ensure anonymity, no personal information was requested other than socio-demographic characteristics including age, education level, occupation for HCPs and patients diagnosis for patient- and relative representatives.

Analysis

The two questionnaires of the first round were merged in Stata (version 17). Stata was used for the analysis and for the recoding of answers submitted in the open-ended text box. When analysing the open field text, we first checked how often the field was filled in. As a guideline, we decided to include a response in the next round when the response was given more often than the least selected pre-defined answer category. However, this was never the case. This suggests that the multiple choice categories were comprehensive enough. Response categories were listed and ordered using frequency tables. Descriptive statistics were used to summarise the data.

Definition of consensus

Consensus was defined as an agreement of ≥ 70% a priori.

Ethical considerations

This study was assessed by the Medical Ethics Committee of Brabant (METC NW2021-71) and exempt from full approval of an ethics committee due to the fact that there was no invasive intervention nor were there vulnerable patients involved (CCMO, 2020). Informed consent was obtained from all panellists. At the start of each questionnaire panellists had to give permission for the data to be used for research by checking a box. They were only able to access the questionnaire after checking the box.

Results

In total, the expert panel consisted of 91 panellists of whom 83 (91%) were HCPs, who were oncology specialists either with or without additional PC training, 6 (7%) were patient representatives and 2 (2%) were relative representatives (Table 1). Of the HCPs involved, 47 (52%) were physicians and 36 (40%) were nurses. The first round was completed by 71 panellists (78%), the second round by 65 (71%) and the third by 49 panellists (54%). The expert panel agreed on 34 out of 55 characteristics of timely integration of PC in oncology.

Table 1 Social demographic characteristics of the expert panel (n=91)

Expert panel	**n (%)**
Sex (n=91)	
Female	71 (78)
Male	20 (22)
Age (years) (n=91)	
Mean (SD)	48 (10.5)
≤ 30	3 (3)
31-40	19 (21)
41-50	16 (18)
51-60	25 (27)
≥60	8 (9)
Missing	20 (22)
Role in expert panel (n=91)	
Healthcare professional	83 (91)
Patient	6 (7)
Relative	2 (2)
Healthcare practitioners' characteristics (n=83)	
Physician	47 (57)
Nurse	36 (43)
Academic hospital (n=71)	30 (36)
Oncology specialist (n=71)	44 (62)
Palliative care specialist (n=71)	25 (18)

Characteristics of current best practices of timely integration of palliative care in oncology

More than half of the HCPs in the expert panel reported that they pay special attention to identifying potential PC needs in all patients with incurable cancer (66%) or only in patients with incurable cancer who also have a poor performance status (66%) (Table 2). The majority of HCPs reported that they pay particular attention to identifying potential PC needs when patients have an increased symptom burden (65%), shortly after being diagnosed with incurable cancer (61%) and/or when patients have a limited life expectancy (less than 3 or less than 12 months) (59-56%). Advance care planning was initiated within the hospital by the SPCT (58%) or by the treating medical specialists (54%). A trigger for the involvement of the SPCT in the care of patients was when patients with identified PC needs requested the involvement of the SPCT (58%).

Table 2 Characteristics of current best practices of timely integration of palliative care in oncology as reported by 71 clinical experts (round 1)

Identification of palliative care needs	
Who – For which patients with incurable cancer do you pay extra attention for identifying potential palliative care needs?	**Yes % (n)**
All patients with incurable cancer	66 (47)
Patients with incurable cancer AND a poor performance status	66 (47)
Patients with incurable cancer AND comorbidity	46 (33)
When – When in the disease trajectory of patients with incurable cancer do you pay extra attention for identifying potential palliative care needs?	
When patients have incurable cancer AND suffer increased symptom burden	65 (46)
When patients are diagnosed with incurable cancer	61 (43)
When patients have incurable cancer AND a life expectancy of < 3 months	59 (42)
When patients have incurable cancer AND a life expectancy of < 12 months	56 (40)
Advance care planning	
Who – For which patients with identified palliative care needs is advance care planning initiated in your hospital?	**Yes % (n)**
Patients with identified palliative care needs AND metastases	41 (29)
When patients have identified palliative care needs AND a life expectancy of < 12 months	38 (27)
When – When in the disease trajectory of patients with identified palliative care needs do you initiate advance care planning?	
When patients are diagnosed with incurable cancer	41 (29)
When patients have identified palliative care needs AND suffer increased symptom burden	41 (29)
When patients have identified palliative care needs AND there is a (possible) switch in line of therapy *	38 (26)
By whom – Who initiates advance care planning?	
Members of the specialist palliative care team	58 (41)
Medical specialists	54 (38)
Patients	41 (29)
Nurse practitioners	39 (28)
Routine symptom monitoring	
Who – For which patients with identified palliative care needs are symptoms routinely monitored in your hospital?	**Yes % (n)**
All patients with incurable cancer	38 (27)
Patients with identified palliative care needs AND metastases	21 (15)
Patients with identified palliative care needs AND a poor performance status	18 (13)
Patients with identified palliative care needs AND metastases of a tumour which gives a life expectancy of < 12 months	17 (12)
When – When in the disease trajectory of patients with identified palliative care needs are symptoms routinely monitored in your hospital?	
When patients have identified palliative care needs AND suffer increased symptom burden	34 (24)
When patients are diagnosed with incurable cancer	28 (20)
When patients have identified palliative care needs AND are unexpectedly admitted to the hospital	23 (16)
When patients have identified palliative care needs AND there is a (possible) switch in line of therapy	21 (15)
By whom – Who monitors symptoms routinely of patients with identified palliative care needs in your hospital?	
Nurse practitioners	42 (30)
Medical specialists	38 (27)
Nurses	30 (21)
Specialist Palliative Care Team	
When – When in the disease trajectory of patients with identified palliative care needs is the specialist palliative care team involved in your hospital?	**Yes % (n)**
Patients have identified palliative care needs AND request their involvement	58 (41)
Patients have identified palliative care needs AND for who death is imminent	44 (31)
Patients have identified palliative care needs AND progression without other treatment options	32 (23)

*Missing n=2

Consensus on characteristics of identifying potential palliative care needs

Nearly all panellists agreed that the PC needs should be assessed for the following patient groups: all patients with incurable cancer (97%), patients with incurable cancer and a poor performance status (97%) and/or patients with incurable cancer and comorbidities (92%) (Table 3). All panellists agreed that the potential PC needs should be assessed at least at the following moments in the disease trajectory: when there is a limited life expectancy of less than three months or less than twelve months (100%-91%), shortly after the diagnosis of incurable cancer (90%), and/or when patients have a high symptom burden (88%).

Consensus on characteristics of advance care planning

The panellists reached a consensus that advance care planning should be initiated for the following patient groups: all patients with identified PC needs (86%) and more specifically for patients with identified PC needs and metastatic disease (77%). Advance care planning should be initiated at least at the following moments in the disease trajectory: when patients with identified PC needs have a life expectancy of less than 12 months (90%), when patients have high symptom burden (79%) and/or when there is a change in the treatment trajectory (70%). The responsibility for initiating advance care planning lies with the treating physician (92%) and nurse practitioner or specialised nurse (80%).

Consensus on routine symptom monitoring

The panellists agreed that it is necessary to routinely monitor symptoms for all patients with incurable cancer and identified PC needs (91%). Additionally, patients with a tumour with an expected life expectancy of less than12 months (95%), patients with a poor performance status (89%) or patients with identified PC needs and metastatic disease (88%) should also have their symptoms routinely monitored. Triggers for the start of routine symptom monitoring included a high symptom burden (98%), an unexpected hospital admission (98%), a (possible) change in therapy (94%) and diagnosis with incurable cancer (82%). Symptoms should be routinely monitored by a nurse practitioner or specialised nurse (94%), a nurse (81%) or a physician (47%).

Consensus on characteristics of introducing a Specialist Palliative Care Team

Panellists agreed that patients should be informed about the SPCT in two situations. Firstly, when they experience an increased symptom burden on multiple dimensions (physical, psychological, social or spiritual) (80%). Secondly, when they have a life expectancy of less than 3 months (73%). According to most panellists this limited life expectancy of less than 3 months was also a trigger for offering patients a consultation with the SPCT (71%). This consultation should be offered by the treating physician (92%) or a nurse practitioner or specialised nurse (86%). Additionally, the SPCT should be involved when patients with identified palliative care needs request their involvement (86%) and/or when patients experience increased symptom burden on multiple dimensions (physical, psychological, social or spiritual) (76%).

Table 3 Consensus on statements regarding characteristics of identification of palliative care needs (round 2 and 3)

Identification of palliative care needs		**Disagree**	**Neutral**	**Agree**
Who – Palliative care needs should be assessed for…	**N**	**% (n)**	**% (n)**	**% (n)**
all patients with incurable cancer	65	2 (1)	2 (1)	**97 (63)**
patients with incurable cancer AND a poor performance status	63	3 (2)		**97 (61)**
patients with incurable cancer AND comorbidity	62	5 (3)	3 (2)	**92 (57)**

When – Palliative care needs should be assessed when…	**N**	**% (n)**	**% (n)**	**% (n)**
Patients have incurable cancer AND a life expectancy of < 3 months	64	-	-	**100 (64)**
Patients have incurable cancer AND a life expectancy of < 12 months	64	-	9 (6)	**91 (58)**
Patients have incurable cancer AND suffer increased symptom burden	65	3 (2)	9 (6)	**88 (58)**
Patients are diagnosed with incurable cancer[1]	49	6 (3)	4 (2)	**90 (44)**

[1] Statement was included in round 3 therefore has a smaller n

Advance care planning		**Disagree**	**Neutral**	**Agree**
Who – Advance care planning should be initiated for…	**N**	**% (n)**	**% (n)**	**% (n)**
Patients with identified palliative care needs	63	6 (4)	8 (5)	**86 (54)**
Patients with identified palliative care needs AND metastases	62	11 (7)	11 (7)	**77 (48)**

When – Advance care planning should be initiated when…	**N**	**% (n)**	**% (n)**	**% (n)**
Patients with identified palliative care needs AND a life expectancy of < 12 months	62	3 (2)	6 (4)	**90 (56)**
Patients have identified palliative care needs AND suffer increased symptom burden	61	2 (1)	20 (12)	**79 (48)**
Patients have identified palliative care needs AND there is a (possible) switch in line of therapy	60	8 (5)	13 (22)	**70 (42)**

By whom – Advance care planning should be initiated by	**N**	**% (n)**	**% (n)**	**% (n)**
The treating physician	64	0 (0)	8 (5)	**92 (59)**
A nurse practitioner or specialised nurse	64	5 (3)	16 (10)	**80 (51)**
A member of the specialist palliative care team	65	34 (22)	31 (20)	35 (23)
The patient	64	34 (22)	41 (26)	25 (16)

Table 3 Continued

Routine symptom monitoring		**Disagree**	**Neutral**	**Agree**
Who – Symptoms should be routinely monitored for…	**N**	**% (n)**	**% (n)**	**% (n)**
Patients with identified palliative care needs AND metastasis of a tumour which gives a life expectancy of < 12 months	63	3 (2)	2 (1)	**95 (60)**
All patients with incurable cancer and identified palliative care needs	65	5 (3)	5 (3)	**91 (59)**
Patients with identified palliative care needs AND metastases	63	5 (3)	8 (5)	**88 (55)**
Patients with identified palliative care needs AND a poor performance status	63	6 (4)	5 (3)	**89 (56)**

When – Symptoms should be routinely monitored when…	**N**	**% (n)**	**% (n)**	**% (n)**
Patients have identified palliative care needs AND suffer increased symptom burden	64	1 (1)		**98 (63)**
Patients have identified palliative care needs AND are unexpectedly admitted to the hospital	62	1 (1)		**98 (61)**
Patients have identified palliative care needs AND there is a (possible) switch in line of therapy	62	1 (1)	5 (3)	**94 (58)**
Patients are diagnosed with incurable cancer [1]	49	8 (4)	10 (5)	**82 (40)**

By whom – Symptoms should be routinely monitored by…	**N**	**% (n)**	**% (n)**	**% (n)**
Nurse practitioners or specialised nurses	64	2 (1)	5 (3)	**94 (60)**
Nurses	62	2 (1)	18 (11)	**81 (50)**
Physicians	62	2 (1)	23 (14)	**76 (47)**

[1] Statement was included in round 3 therefore has a smaller n

Involvement of the specialist palliative care team		**Disagree**	**Neutral**	**Agree**
When – The specialist palliative care team should be involved when…	**N**	**% (n)**	**% (n)**	**% (n)**
Patients have identified palliative care needs AND request the involvement of the specialist palliative care team	63	3 (2)	11 (7)	**86 (54)**
Patients have identified palliative care needs AND suffer increased symptom burden on multiple dimensions (physical, psychological, social or spiritual) [1]	49	16 (8)	8 (4)	**76 (37)**
Patients have identified palliative care needs AND progression without other treatment options	63	21 (13)	39 (24)	41 (26)
Patients have identified palliative care needs AND death is imminent	63	22 (14)	38 (24)	40 (25)
Patients have identified palliative care needs AND suffer increased symptom burden of two or more symptoms [1]	49	35 (17)	43 (21)	23 (11)

Informing patients about the specialist palliative care team		**Disagree**	**Neutral**	**Agree**
Who – Information about the specialist palliative care team should be given to…	**N**	**% (n)**	**% (n)**	**% (n)**
Patients with identified palliative care needs AND a poor performance status [1]	49	16 (8)	14 (7)	69 (34)
Patients with identified palliative care needs AND comorbidity [1]	49	14 (7)	23 (11)	63 (31)

Table 3 Continued

When – Information about the specialist palliative care team should be given when…	**N**	**% (n)**	**% (n)**	**% (n)**
Patients have identified palliative care needs AND suffer increased symptom burden on multiple dimensions (physical, psychological, social or spiritual)[1]	49	8 (4)	12 (6)	**80 (39)**
Patients have incurable cancer AND a life expectancy of < 3 months[1]	49	18 (9)	8 (4)	**73 (36)**
Patients have incurable cancer AND a life expectancy of < 12 months[1]	49	18 (9)	16 (8)	65 (32)
Patients are diagnosed with incurable cancer[1]	49	14 (7)	31 (15)	55 (27)
Patients have identified palliative care needs AND suffer increased symptom burden of two or more symptoms[1]	49	20 (10)	29 (14)	51 (25)
Patients have identified palliative care needs AND suffer increased symptom burden[1]	49	29 (14)	24 (12)	47 (23)

By whom – Information about the specialist palliative care team should be given by…	**N**	**% (n)**	**% (n)**	**% (n)**
The treating physician[1]	49	2 (1)	8 (4)	**90 (44)**
A nurse practitioners or specialised nurses[1]	49	4 (2)	10 (5)	**86 (42)**
A nurse[1]	49	8 (4)	29 (14)	63 (31)

Offering patients a consultation with the specialist palliative care team		**Disagree**	**Neutral**	**Agree**
Who – A consultation with the specialist palliative care team should be offered to	**N**	**% (n)**	**% (n)**	**% (n)**
Patients with identified palliative care needs AND a poor performance status[1]	49	20 (10)	20 (10)	59 (29)
Patients with identified palliative care needs AND comorbidity[1]	49	14 (7)	31 (15)	55 (27)

When – A consultation with the specialist palliative care team should be offered when…	**N**	**% (n)**	**% (n)**	**% (n)**
Patients have incurable cancer AND a life expectancy of < 3 months[1]	49	16 (8)	12 (6)	**71 (35)**
Patients have identified palliative care needs AND suffer increased symptom burden on multiple dimensions (physical, psychological, social or spiritual)[1]	49	10 (5)	20 (10)	69 (34)
Patients have incurable cancer AND a life expectancy of < 12 months[1]	49	18 (9)	20 (10)	61 (30)
Patients have identified palliative care needs AND suffer increased symptom burden of two or more symptoms[1]	49	18 (9)	27 (13)	55 (27)
Patients are diagnosed with incurable cancer[1]	49	29 (14)	27 (13)	45 (22)
Patients have identified palliative care needs AND suffer increased symptom burden[1]	49	29 (14)	31 (15)	41 (20)

By whom – A consultation with the specialist palliative care needs should be offered by	**N**	**% (n)**	**% (n)**	**% (n)**
The treating physician[1]	49	2 (1)	6 (3)	**92 (45)**
A nurse practitioners or specialised nurses[1]	49	4 (2)	10 (5)	**86 (42)**
A nurse[1]	49	10 (5)	22 (11)	67 (33)

[1] Statement was included in round 3 therefore has a smaller n

Discussion

This Delphi study has identified essential characteristics of four main elements of timely integration of PC into oncology hospital care: identification of potential PC needs, ACP, routine symptom monitoring, and the involvement of the SPCT.

Identification of potential palliative care needs

Studies have shown that timely PC has benefits, such as improved quality of life [5, 7]. Although several screening tools are available to help assess potential PC needs, including the Surprise Question (SQ) and the Supportive and PC Indicators Tool (SPICT) [18], structural assessment of PC needs is often not part of daily clinical practice in the Netherlands [19]. The expert panel agreed that the PC needs should indeed be assessed for all patients with incurable cancer, immediately after diagnosis. It is important to note that the PC needs of patients with incurable cancer change over time [20]. Therefore, identifying potential PC needs should be seen as an ongoing process, that starts at diagnosis and continues throughout the disease trajectory [9]. In the last six months of life, patients often experience a steady increase in physical symptoms such as fatigue, pain and dyspnoea as well as psychological distress [21, 22]. However, identifying PC needs in a timely manner can be challenging due to overly comprehensive tools with many items, administrative burden and time limitations. Developing accurate and practical screening tools is essential for daily clinical care. One such tool is the double surprise question [23].

Advance care planning

There is growing evidence of the beneficial effects of ACP, including less life-sustaining treatment and hospitalisation at the end of life, increased use of hospice and PC, better compliance with patients' end-of-life wishes and improved concordance between preferences for care and care provided [24, 25]. International recommendations state that ACP should be initiated early in the disease trajectory of patients with a life-threatening disease [26]. This is consistent with the finding that the expert panel fully agreed that ACP should be initiated in all patients with PC needs. According to the panellists, other potential triggers for initiating ACP included a life expectancy of less than 12 months (e.g. identified by using the SQ) and high symptom burden. However, implementation of ACP in daily oncology practice is challenging and unfortunately the uptake is still limited [27]. There are known barriers to the implementation of ACP at the organisational and the individual psychological levels. Barriers at the organisational level include insufficient integration into the workflow, lack of involvement of HCPs in the ACP-process and its outcomes [28], lack of a structured place for ACP in the electronic patient record, lack of proper handover of ACP plans between involved HCPs in primary and secondary care [29] and lack of time [30]. Barriers on the individual psychological level are the fear that ACP discussions will lead to depression or loss of hope [31]. Ineffective patient-physician communication [32] may result in infrequent and untimely ACP discussions.

Routine symptom monitoring

The integration of routine symptom monitoring into daily clinical practice is still suboptimal, leading to underestimation of symptoms [33]. Nevertheless, the panellists almost all agreed that symptoms should be monitored for all patients with incurable cancer and identified PC needs (Table 3). This is likely to be influenced by an increasing number of studies showing the negative association between symptom burden and quality of life [34, 35]. Furthermore, the integration of patient-reported outcomes into routine symptom monitoring into oncology care is associated with increased survival rates for patients with metastatic disease [36]. However, there are still barriers to overcome regarding the tool with which symptoms could be monitored. A tool should not be burdensome for patients, families and HCPs [37], it should take all four dimensions into account (physical, social, psychological and spiritual) [38] and should be accessible to patients from different backgrounds and with different levels of language proficiency and health literacy. In case of a digital tool, the well-known barriers are the costs of a system, storage and data security [39].

Specialist palliative care (consultation) team

According to our expert panel, a short life expectancy (less than 3 months) seems to be the trigger to inform all patients with identified PC needs about the SPCT team or to offer them a consultation. It is important to realise that this is set as a minimum use of specialist palliative care, more is possible if needed. This minimal use of SPCT in the Dutch setting is important to ensure equal access to SPCT for all patients with incurable cancer. From previous studies in the Netherlands, we know that SPCTs are still involved (too) late and to a limited extent [19]. The results of this study could be a first step in the right direction, which means a minimum use and therefore access for all cancer patients with a limited life expectancy. Despite it being rather late, this trigger of a short life expectancy is in line with current practice, which shows that most referrals concern patients in the last weeks before their death [19]. This late referral may be related to the disease trajectory of incurable cancer patients, with a rather steep decline in (health-related) quality of life in the last three months [40].

The panellists also indicated that the SPCT should be consulted when patients with cancer have an increased symptom burden on multiple dimensions, indicating complexity. This is in line with the mixed generalist-specialist model of PC in the Netherlands. However, defining the complexity in patients with incurable cancer is challenging. A recent systematic review identified different classification systems for complexity of patient needs in PC and concluded that more research is needed to integrate these classification systems into clinical cancer care [41].

Overall, there appears to be some reluctance to define triggers for standard involvement of the SPCT, as the expert panel only reached consensus on two statements: the SPCT should be involved when patients request their involvement, and when patients with identified PC needs have an increased symptom burden on multiple dimensions. The expert panel did not consider disease progression without other treatment options, an imminent death, or increased symptom burden of two or more symptoms to be reasons for standard involvement of the SPCT in patients with identified PC needs. The diagnosis of incurable cancer, a life expectancy of less than 12 months, increased symptom burden (of two or more symptoms) were also not found to be moments when patients should be informed about or offered a consultation with the SPCT. A possible explanation could be that in the generalist-specialist model, the PC generalist should be well equipped to provide PC to patients whose disease trajectory are without major complications. For more complex palliative care needs, general practitioners can consult palliative care specialists. Therefore, our results may not be consistent with other international publications as our results are tailored to current clinical practice in the Netherlands. Furthermore, the majority of European and American medical oncologists consider end-of-life care to be an integral part of their work [42]. However, this means that PC generalists must have a sound knowledge of PC and communicative skills [43]. In addition to communication skills, there are still some other barriers that need to be overcome for PC generalists to effectively integrate PC into their clinical work, such as lack of time and lack of formal training [44].

Strengths and limitations

This modified Delphi study used a multidisciplinary expert panel, including the patients' perspective, to identify elements and essential characteristics of timely integration of PC into oncological care. The study had a high response rate. Some limitations need to be considered. The convenience sampling method used to recruit panellists may have introduced some selection bias. The regional PC consortia were asked to contact the hospitals through their contact person. This person was often a member of the SPCT. This person then contacted the PC generalists, which is likely to result in panellists who are aware of PC in general and of the SPCT and its role. The response rate was good, but it declined towards the third round which may have slightly biased the results. In addition, the questionnaires used were designed and pilot tested by the researchers, but not validated. Finaly, there is no official guideline or definition of consensus. Therefore, this study uses the definition of consensus based on other studies within PC research [8, 45].

Conclusion

Panellists agreed that for all patients with incurable cancer potential PC needs should be assessed soon after patients are diagnosed with incurable cancer. Panellists also agreed that once patients' PC needs have been identified, ACP and routine symptom monitoring should be initiated. SPCTs should be involved when patients have a high symptom burden on multiple dimensions or when patients have a short life expectancy of less than 3 months. In terms of future research, a deeper understanding of how to structurally integrate the assessment of potential PC needs, ACP and symptom management into oncology care is needed. It also calls for more educational resources on PC for all HCPs to enable them to provide generalist PC for patients with incurable cancer.

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CHAPTER 3

Timely integration of palliative care into standard oncology care: an interview study with healthcare professionals and patients with incurable cancer

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Abstract

Objectives Timely integration of palliative care (PC) into standard oncology hospital care offers significant benefits to patients with incurable cancer and their families. International recognition of the importance of timely palliative care has shifted the focus from integration to determining the optimal timing for introducing PC. The specific care responsibilities of oncology clinicians acting as generalists in palliative care and the optimal timing for involving palliative care specialists remain uncertain.

Aim This study aimed to 1) explore how the concept of 'timely PC' is understood by oncology clinicians and patients with incurable cancer and 2) investigate how PC is provided in a timely manner in daily clinical practice.

Methods An interview study was conducted with 18 oncology clinicians (7 physicians, 1 physician assistant and 10 nurses/nurse practitioners) and 12 patients with incurable cancer. The interviews were conducted between October 2022 and June 2023 and a thematic analysis of the interviews was performed.

Results Three main themes emerged regarding 'timely PC': 1) timely PC is individual and situational, 2) identification of the right time is an ongoing challenge, 3) proactive care is essential. Regarding the provision of timely PC three themes were identified: 1) having a strong collaboration among various clinicians, 2) having the courage to start a clear and sincere conversation, and 3) being sensitive and personal.

Significance of results Being timely is not a fixed point in time, but depends on the individual patient and their situation. Clinicians should be proactive and gradual in bringing up PC-related topics and be careful to use the right words. Tools such as the surprise question can support in timely integrating palliative care but being timely palliative care highly depends on a patient's individual context. Therefore, clinicians should be aware that timely palliative care is a constant search for the most fitting moment.

Introduction

With the expected increase in cancer incidence over the coming decades, it has been predicted that by 2040 cancer will be one of the main drivers of palliative care (PC) needs [1, 2]. Timely integration of PC into the care of patients with incurable cancer and their families has been shown to improve quality of life and satisfaction with care, reduce symptom burden and potentially inappropriate end-of-life care, and may even improve survival rates [3-7]. This extensive body of literature has led to international guidelines and recommendations from high-level associations, such as the American Society of Clinical Oncology (ASCO), which states that PC should be integrated within eight weeks of diagnosis of advanced cancer [8]. A consensus study among members of the Multinational Association of Supportive Care in Cancer (MASCC) and the European Society for Medical Oncology (ESMO) identified thirteen indicators of oncology and PC [9]. This international recognition of the importance of timely PC has shifted the focus from whether PC should be integrated into standard oncology care to identifying the optimal timing for its introduction.

The Dutch healthcare system adopted an integrated generalist and specialist PC model, in which all clinicians provide basic PC based on their medical training. This includes basic symptom management and discussion of prognosis and treatment goals [10, 11]. When needed, such as in complex symptom burden, clinicians in the hospital are supported by consultants of the specialist PC team (SPCT). These PC consultants are nurses, nurse specialists or physicians with additional expertise and broad experience in PC. Since 2017 every Dutch hospital caring for oncology patients is obliged to have a SPCT. Clinicians can call upon the PC consultants for peer-to-peer consultation or they can refer patients and their families. It has been suggested that the generalist-specialist model is the most feasible model for integrating PC into oncology, since there are not enough PC consultants to attend to all patients with PC needs [10, 12]. Ensuring timely PC within this model means both timely generalist PC: all clinicians should be able to identify potential PC needs and have adequate communication skills to discuss and manage basic PC needs, as well as timely specialist PC: clinicians should consider involving a PC consultant of the SPCT and do so when needed, in a timely manner.

Previous studies on the integration of PC in oncology have looked at when patients should be referred to a PC consultant, often using the word 'early' instead of ‘timely’. ‘Early’ was defined as a specific point in time (e.g. within two months of diagnosis of advanced cancer [13, 14]), prognosis [4] or a combination (estimated prognosis of < 12 months and within 3 months after diagnosis [3]). ‘Timely’ PC does not necessarily refer to a specific point in time, but rather to care that is tailored to the needs of the patient and family, and provided at the optimal time and setting [15]. However, there is no concrete definition of timely generalist PC that describes when oncology clinicians should integrate PC into their standard care. It also remains unclear which moment is the most optimal for timely referral to PC consultants [16-18].

Therefore, the aims of this study were 1) to explore how the concept of ‘timely PC’ is understood by oncology clinicians and patients with incurable cancer and 2) investigate how PC is provided in a timely manner in daily clinical practice.

Methods

Study design

An interview study was conducted using semi-structured interviews. The Consolidated criteria for Reporting Qualitative research (COREQ) were used for reporting [19].

Participants and setting

Three hospitals were selected based on the following information: prior participation in a Delphi study on integrated care, in which 21 Dutch hospitals took part [20]; data from a national survey of Dutch hospital-based SPCTs, that included the assessment of PC integration indicators (e.g., inpatient services, outpatient clinics, interdisciplinary staffing, early referrals, symptom monitoring, and curriculum adherence) [21]; adherence to SONCOS guidelines, which serve as a benchmark for oncological care quality [22]; individual clinician interviews to further understand each hospital’s PC practices; hospital type (one academic and two non-academic), and spread across the Netherlands. Based on these assessments, the research team reached consensus on the final selection. To ensure a broad perspective on the timely integration of PC, different types of oncology clinicians (nurses, nurse specialists, physician assistants and physicians) working in different departments of the hospital (medical oncology, haematology, gastroenterology and pulmonary), with and without additional

PC training were invited to participate in an interview. Patients were recruited in the three participating hospitals. Eligible patients included inpatients and outpatients diagnosed with incurable cancer, aware of their diagnosis and able to speak Dutch. Patients were interviewed to obtain new insights and topics besides those obtained by the interviews with clinicians. Patients' perspectives were considered complementary to those of clinicians.

Recruitment

We used purposive sampling for the recruitment. The criteria for purposive sampling for clinicians were: treating patients with incurable cancer, having additional expertise and knowledge of palliative care or not having this additional expertise. Clinicians were recruited via a designated contact in each hospital, who reached out to colleagues and forwarded the email addresses of those interested. The researcher then emailed them a description of the study and invited them for an interview. The interviews were conducted either at the hospital or online. Face-to-face participants received an informed consent form before the interview, and the online participants signed and returned the forms by email.

The criteria for purposive sampling for patients were: being diagnosed with incurable cancer and aware of this diagnosis, a minimal age of 18 years and the ability to speak Dutch. Eligible inpatients were approached by their treating clinician or by the PC consultants of the SPCT and then contacted by the researcher (CH) to confirm that they had read the information and were willing to be interviewed. Eligible outpatients received the information leaflet during a visit to the outpatient clinic and, after consent, had their contact details securely emailed to the researcher (CH), who then arranged an interview at the hospital or the patient's home.

Data collection

Two topic lists were developed, one for clinicians and one for patients (Supplementary material I and II). The topic lists were based on key publications regarding timely integration of PC in oncology [11, 16] and the domains of PC as defined in the Netherlands Quality Framework for PC [23]. The patient topic list was pilot-tested with two patient representatives after which it was slightly adapted (Supplementary material II). All interviews were conducted between October 2022 and June 2023 by CH, a female researcher with a background in anthropology. The average length of the interviews was 35 minutes for clinicians and 69 minutes for patients.

All interviews were audio-recorded and transcribed verbatim. The process of data collection was cyclical and iterative, with the researchers (CH and LB) analysing the interviews after they had taken place and discussing emerging findings. Interviews were conducted until saturation was reached.

Data analysis

Thematic analyses were conducted according to the six stages described by Braun et al. [24] using the qualitative software package ATLAS.ti (version 23.1.1) [25]. Interviews with clinicians and patients were analysed separately. The analysis of the clinicians' data was completed first. During the patient interviews and data analysis, many connections were observed. Therefore, it was decided to merge the two coding trees. Two researchers (CH and LB) independently coded two transcripts to establish the inter-observer reliability of the coding procedure [18]. The constant comparative method was used to compare codes within and across interviews. CH coded the other transcripts and the codes were discussed in frequent meetings with the research team (CH, LB, NR). Relevant quotations were selected to illustrate the themes.

Ethical consideration

The study was conducted according to the Declaration of Helsinki. The Medical Ethics Committee of Brabant (NW2021-71) reviewed the study and exempted it from full approval of an ethics committee (CCMO, 2020). Written informed consent for participation (and recording) was obtained from all individual participants. In addition, the Dutch Personal Data Protection Act was followed in the data collection and analyses procedures.

Results

A total of 18 clinicians and 12 patients were interviewed. The majority of clinicians was female (78%), and most patients were male (58%). The median age of the clinicians was 43 years (range 29-61), and the median age of the patients was

64 years (range 56-83). 72% of clinicians had additional training in PC (Table 1). In seven patient interviews, the partner was also present during the interview to support the patient.

Table 1 Sociodemographic characteristics of clinicians (n=18) and patients (n=12)

	Clinicians	Patients
Age in years (median, range)	43 (29-61)	64 (56-83)
	n (%)	**n (%)**
Sex		
Female	14 (78)	5 (42)
Male	4 (22)	7 (58)
Hospital type		
Academic	6 (33)	5 (42)
Teaching hospital	5 (28)	2 (17)
Community hospital	7 (39)	5 (42)
Profession		
Oncology nurse	5 (28)	
Nurse practitioner oncology	5 (28)	
Medical oncologist	4 (22)	
Other physicians	4 (22)	
Additional training in PC	13 (72)	
9-day course in palliative care for physicians	5 (38)	
2-years palliative care CME[1] for physicians	1 (8)	
Nurses with 1-year palliative care CNE[2]	7 (54)	
Marital status		
Married		7 (58)
In a relationship, living together		2 (17)
In a relationship, not living together		1 (8)
Living alone/widowed		2 (17)

[1]CME: Continuing medical education; [2]CNE: Continuing nursing education

In exploring 'timely PC', three main themes emerged from the analysis of both the interviews of clinicians and patients, namely 1) timely PC is individual and situational, 2) identifying the right time is an ongoing challenge and 3) proactive care is essential. In the context of providing timely PC in a generalist-specialist model, three further themes were identified, namely the importance of 1) having a strong collaboration among various clinicians (between both physicians and nurses, and PC-generalists and the PC consultants), 2) having the courage to start a clear and sincere conversation, and 3) being sensitive and personal (Table 2). All themes are described below from the perspective of clinicians and patients.

Table 2 Identified main themes per subject

1. Exploring the concept of 'timely PC'	**Identified main themes**
	1.1 Timely PC is individual and situational
	1.2 Identifying the right time is an ongoing challenge
	1.3 Proactive care is essential
2. How timely PC is delivered a generalist-specialist model	**Identified themes**
	2.1 Having a strong collaboration between various clinicians
	2.2 Having the courage to start a clear and sincere conversation
	2.3 Being sensitive and personal

1. Gaining a deeper understanding of timely PC

Theme 1.1: Timely PC is individual and situational

Clinicians found it challenging to define when initiating discussions about care preferences, possible future scenarios or referring patients to a PC consultant was considered 'timely'. Clinicians said it was difficult to identify a specific point in time that could be expressed in months or years. Rather, they spoke of moments in the disease trajectory, such as (shortly after) diagnosis of incurable cancer, when symptom burden is high, or when there is a possibility that the next treatment will not be effective.

> I think it [timely] is when you get to a point where the therapy might cause problems or that you arrive at yet another line of treatment. But I find it quite difficult to be very black and white; when is timely? It depends on the individual, of what is going on, the context of the patient and how urgent is it to have certain conversations with people. (Oncology nurse practitioner)

Clinicians reported that the timing varied from patient to patient and was strongly influenced by patients' attitudes and coping strategies. Clinicians initiated advance care planning discussions earlier (e.g. shortly after diagnosis of incurable cancer) with patients who were open and had discussed their care wishes with family members compared to patients who were reluctant to discuss anything besides anticancer treatment.

> More than half of our patients arrive with a stage IV disease, so that means that the treatment that is started is a palliative treatment. How much time and attention is spent on discussing the palliative part or the systemic therapy very much depends on the patient's symptom burden and how the patient feels. If you have a very young person with a relatively low tumour load that you give a treatment that you most likely can prescribe for quite a long period, then discussions will be a bit more focused on symptoms that the patient copes with, the current treatment and side effects. (Pulmonologist)

Clinicians did not identify a specific point in time with regards to the timely involvement of a PC consultant. Rather, they involved them there was a combination of aspects that made the situation difficult.

> Often it's the complex patients, for example, if they have a vulnerable situation at home which makes living at home impossible. Or patients with physical problems, such as pain that cannot be managed properly or in case of difficult palliative sedation. But also when you notice that a patient has a lot a lot going on for which you want additional expertise, then you often consult the specialist palliative care team. (Oncology nurse)

Clinicians who felt confident in providing generalist PC referred patients to a PC consultant when they felt they could not really reach the patient, could not put their finger on the patient's problem and therefore felt they could benefit from the fresh perspective of a PC consultant.

> Especially if you have known a patient for a longer period of time you start to see him or her in a certain way. That's when I like getting my colleagues' opinion. And it's also very nice for patients, who sometimes try very hard to tell me that everything is going great because I am the gatekeeper to their next treatment, to talk to someone else about what they would like if things are not going well. (Medical oncologist).

In their efforts to define timely PC, patients reflected on their own experiences and expressed that their perspective might be different from that of other patients. Having specific symptoms or needs (e.g. questions about their illness and prognosis or fears) and different moments in the disease trajectory (e.g. after being diagnosed with incurable cancer and being on the last line of anticancer treatment) were considered timely moments for integrating PC. Patients differed in whether they experienced feeling physically and mentally well as timely. Some did, while others wanted to focus on their anticancer treatment while things were going well.

> I would have appreciated it if two weeks after [diagnosis of incurable cancer] there had been an appointment with a palliative care consultant who would have told me a bit more about what was going on. That my diagnosis does not mean that you die immediately and that you can still go through chemotherapy or radiotherapy, not to get better, but to prolong your life. (Patient)

Theme 1.2: Identifying the right time is an ongoing challenge

When trying to define timely PC, clinicians often referred to situations where PC was either integrated too late or too early. Examples of PC being integrated too late were in the case of a (medical) crisis or when patients were already experiencing a high symptom burden. However, discussing quality of life or introducing the possibility of meeting with a PC consultant at a patient's first appointment after being diagnosed with incurable cancer was considered too early. At this time, patients may be too emotional and overwhelmed.

> It's just very difficult to make a proper assessment of how things are going to go. There are a lot of uncertainties. And patients can also become anxious if they are in an early phase of treatment, when you do not know if you are going to respond to a treatment, and you mention the specialist palliative care. It can make patients wonder if we are doing everything we can to make the treatment work. (Pulmonologist)

Clinicians also stated that they needed time to build trust and rapport before discussing possible future scenarios and a patient's care wishes for when the anticancer treatment is no longer effective.

> I do not do it [ask about care wishes or possible future scenario's] when I see people for the first time. Often, you have known patients a bit longer and therefore they feel a bit safer to talk about these topics. And some patients quite clearly say that they would like to leave it for now and that it will come in due course, while others give you a more extensive reply, that can be very different. (Oncology nurse practitioner)

Patients also felt that it was too early to start talking about PC during the appointment at which they were first told that their cancer was incurable. They expressed that they needed time before they felt able to discuss care preferences and treatment options. This time was needed to mentally process the diagnosis, the impact it might have on their lives, and to focus on the anticancer treatment.

> In the first phase, the first six months, the first year, you need to get your thoughts in order and you have to start organising things. During that time so much is happening in your life besides treatment. (Patient).

Theme 1.3: Being timely means being proactive

Clinicians' examples of how they integrated PC showed a very proactive approach. They elaborated on looking ahead and actively discussing the possible consequences of certain treatment options, even when there was no immediate reason to do so or, for example when patients had a life expectancy of months or years.

> And what I also often try to do, when things are going well and you actually have time to spare, is not to think, well, things are going well now and I will be done in ten minutes and I will be well ahead of my clinic, but to ask, well, how are things actually going? Or do you ever think about what it might be like in the future? (Oncology nurse practitioner)

According to clinicians, proactively integrating PC was a gradual process. This meant that PC-topics were not discussed in a single conversation but were spread out over several appointments. Early in the disease trajectory, clinicians tend to focus on the physical dimension and explaining the disease. Later in the disease trajectory, they addressed topics related to other domains (psychological, social and/or spiritual).

> We know that if you talk about palliative care too late, people may feel that they have not had time to really think things through. So it is good to mention it early, but sometimes you have to take it step by step. For example, you might mention palliative care at a patients' first appointment, just to give them something to think about. That also gives you a sense of whether the patient is open to it or not. (Pulmonologist)

Clinicians emphasised the importance of being able to prioritise what to discuss now and what to discuss later in order to integrate PC proactively and gradually. In their view, introducing a particular PC-related topic does not necessarily mean that it had to be fully explored. Topics might remain unaddressed for months, but briefly mentioning them early on can make it easier to discuss them in depth later.

> Paying attention doesn't mean that you have to do everything right away. But that you can say: 'Well, I hear a number of things in your story that need attention (...). What are things that are important now and what can wait until next time? Or should we involve someone else to help with those worries?' You can also make a kind of roadmap with patients, what needs to be done today and what can be done another time. (Medical oncologist and consultant of the SPCT)

Patients varied in their willingness to proactively discuss non-physical issues, potential future scenarios, or their care preferences. Some wished they had been informed earlier about the possibility of seeing a PC consultant right after being diagnosed with incurable cancer, while others only felt ready when their symptoms worsened or when they reached the final stage of anticancer treatment. Patients also highlighted the importance of a gradual approach to integrating PC.

> I do not think you need to talk about it every time. We have discussed it [end-of-life topics], so at this moment I do not see the need to discuss it again. By the time I get sicker we will pick it back up, that is how I feel. I do not think I need to talk about my final phase every time. I cannot say if that is different for someone else, but that is my opinion. I do not have to talk about my illness trajectory and how I am coping every time. (Patient)

2. Providing timely PC in daily practice in a generalist-specialist model

Theme 2.1: Strong collaboration between clinicians

Clinicians explained that a strong collaboration was essential for the timely integration of PC. This included the collaboration between different disciplines (e.g. medical oncologists and spiritual counsellors), between physicians and nurses, and between PC-generalists and PC consultants. Clinicians stated that strong collaboration and short lines of communication allowed them to draw on each other's expertise, providing different perspectives on patients' symptoms. Additionally, clinicians highlighted how close collaboration between treating physicians and nurses contributed to earlier identification of PC needs, for they have different focuses and complementary skills in caring for patients. Nurses mentioned that their training, skills and experience made them feel equipped to explore symptoms in all four dimensions: physical, social, psychological and spiritual.

> The advantage of being a nurse is that you see a patient very often. Compared to a doctor, you more often hear a patient say what they want or do not want. Another advantage is that a nurse does not have the 'burden' of medical knowledge, where you think: according to studies there is a 2% chance that a patient will make it through. Nurses just look at a patient and think about what it is they notice in a patient; is he deteriorating or not, last admission he was still walking, now he can no longer go to the toilet on his own? (Nurse turned physician assistant gastrointestinal and liver diseases)

Strong collaboration between PC-generalists and PC consultants was seen as essential for timely integration of specialist PC. Clinicians mentioned that the approachability of PC consultants was key, not only in terms of logistics such as being easily accessible and having time to see patients, but more importantly through their open and supportive attitude. Consequently, clinicians did not experience any barriers to approach and involve a PC consultant.

> They always respond very normally, it is never too much. They are never angry or irritated. When you call them, they always check if there is time. And they always say that they really appreciate you calling them and that they will make sure they come over. (Oncology nurse)

The role of nurses in the timely identification of PC needs was also highlighted from the patients' perspective. Patients felt more comfortable expressing their feelings to nurses, because nurses dedicated time to listening, asked more and varied questions, and fostered a more personal connection.

> The nurse asks about [my emotional wellbeing]. Last time when I spoke to her I cried and it all came out. I think the doctor is more for the treatment and with the nurse we have more conversations about my mental health and emotions. I don't think the doctor has time for that, his responsibility and focus is more on the treatment I think. (…) [The nurse] asks different questions. It's more of a chit-chat. With the oncologist you talk more about the kind of treatment we are going to do and with [the nurse] it is more about how things are going. Yes, more chit-chatting. Maybe more about the person behind the disease. (Patient)

Theme 2.2: Having the courage to start a clear and sincere conversation

Clinicians emphasised the importance of using the right words to integrate PC in a timely and well-received manner. This included providing clear explanations about PC, while being sincere about treatment prospects and potential side effects. According to clinicians, these conversations require courage, as the topics are sensitive and it is never certain how a patient will respond. Nevertheless, they emphasised the importance of having the courage to initiate these conversations.

> When people are obviously incurably ill, I do not think you should hide that. So already at our first appointment I tell all my patients: you are not going to get better from this and the chances are very high that you will die from this. We still have these and these treatments to go, we are going to focus on that as well. We are obviously going to hope that you will live to be 100, but at the same time I also want to focus with you on what if you do not. (Medical oncologist)

Although they were sincere and clear, clinicians were still very careful about how they phrased things. They had seen how patients could become anxious or think that their health was rapidly deteriorating if PC-related topics were introduced without a certain degree of subtlety.

> Over the years I have noticed how important it is how you deliver and introduce [PC-related topics]. Because people may be shocked and think: everything was going well and now you are bringing this up, that must mean that I will probably die soon. So you really have to introduce it in a sense of: it is not relevant right now because things are going really well, but it ever does become relevant, what do you think about this or that? Or do you already have wishes or thought about it or how do you feel about it? So that you bring it with some caution. (Oncology nurse practitioner and case manager)

Patients also reflected on the way in which PC was introduced during the course of their disease. They felt that the key was to give a clear explanation of what PC is and how it can support them and their families.

> You have to start with telling people that there is a department and can help you to make it as bearable as possible, to ensure you keep enjoying the things you enjoy doing. And if you are missing anything, then they can see what you need. A special chair, a wheelchair, this or this or that. Then later you can say 'and we call that palliative care'. (Patient)

When patients are first offered a consultation with the SCPT, they found it very important to be given a clear definition of PC and an explanation of the role of a PC consultant. A clear definition takes away any initial fears and associations with terminal care.

> [When introducing the SPCT the physician assistant] said nowadays if you have cancer that does not mean you die immediately. There are so many good medicines with which people have a longer life expectancy. That is why it might be helpful to see the specialist palliative care team, so you can draw your horizon a bit more closer towards you. (Patient)

Theme 2.3: Being sensitive and personal

Clinicians were asked how they identified patients' PC needs in a timely manner when they were not using a specific timeline to integrate PC. The examples they gave illustrated their tactfulness and sensitivity to issues that patients did not always express verbally. They explained that to achieve this, they used skills as actively listening to patients' stories and asking follow-up questions to uncover and identify the underlying PC-needs.

> Sometimes you do not measure being sick by blood values, you measure it by what someone will or will not be able to do in the future. So before anything else listen closely to the patient and do not rush into medical details and start a whole conversation based on medical reasoning. First hear how the patient sees their life and what they want or do not want to endure in order to undergo that treatment, because that is basically what it comes down to. (Nurse turned physician assistant gastrointestinal and liver diseases)

When patients were asked what they appreciated about their treating physician they often did not reflect on their technical skills or knowledge but instead focused on their attitude, using words such as involved, open, warm, compassionate, empathetic, gentle, humorous, sincere and transparent. This attitude made patients feel comfortable asking anything and allowed for a more open discussion about treatment and care preferences.

> You do notice that some doctors are more human-doctors, others are doctor-doctors. For example, whenever I call my own gastroenterologist she will call back the same day. When I called my urologist [previous treating physician] he did not call back. (…) He was very businesslike. As if I was just another patient. With all due respect, I did not feel like that was the doctor with whom I actually had a connection as a human being. I thought why do you not ask about my thoughts, what and how I feel and what I choices I want to make? (Patient)

Discussion

Main findings

This qualitative study shows that clinicians and patients with incurable cancer view ‘timely PC’ as individual and situational, rather than a fixed point in time. This requires a constant search for the most fitting moment to integrate PC, for which a proactive and gradual approach is essential. In daily clinical practice, PC is delivered in a timely manner through a strong collaboration between various clinicians. As clinicians find PC a sensitive topic they start integrating it by showing courage (just doing it), using the right words and being sincere. Important communicative skills for discussing PC include being sensitivity to issues underlying a patient’s story and maintaining a personal approach. Patients also value this personal connections, as it makes them feel they can ask and say anything.

How communication and a clear understanding of PC can help in the search for the fitting moment

The finding that clinicians found it difficult to define timely PC in a concrete and unambiguous way is consistent with a qualitative study that found that clinicians had different understandings of when to initiate discussions about foregoing anticancer treatment at the end of life [26]. That study found that clinicians use different approaches to initiate these discussions. The anticipatory approach, i.e. preparing patients gradually throughout the course of the disease, seems most in line with what both clinicians and patients in this study consider optimal for timely integration of PC. However, foregoing anticancer treatment is only one of many PC-related topics, moreover, at the end of life is late rather than timely. Other studies on timely integration of PC focus on timely referral to a PC consultant but do not discuss timely generalist PC [15, 18, 27].

Our study shows that timely generalist PC is not one-size-fits-all and both clinicians and patients emphasised the importance of considering the individual patient and their situation. This ongoing assessment of a patient’s character and situation is particularly important as clinicians’ perspectives may differ from those of patients. For example, our study shows that when patients are feeling well, clinicians view this a timely moment to proactively integrate PC, whereas patients were more ambivalent about wanting to discuss PC when they were (still) feeling well.

Despite the difficulty of defining the concept of timely PC as a fixed point in time, some form of standardised moments at which to integrate PC is necessary. This standardisation ensures that the timely integration of PC does not depend solely on clinicians' training or patients' preferences, and thereby preventing PC from being integrated too late, as is often the case in current daily clinical practice [28, 29]. In the Dutch context of a generalist-specialist model, this standardisation is twofold: standardised moments for integrating generalist palliative care (including symptom management and assessment and initiating advance care planning discussions) and standardised moments for involving a PC specialist. Standardisation for both the integration of generalist and specialist PC can be embedded through care pathways [30, 31], automated alerts in the electronic health record [32, 33], or the development of guidelines and recommendations for the timely integration of PC into oncology [8, 11, 34-36]. .

Results of this study show that the most optimal moment for integrating timely PC in a generalist-specialist model should be based on a patient's needs rather than on a specific point in time [37]. This calls for a structural discussion of patients' needs and monitoring of symptoms in all four dimensions (physical, psychological, social and spiritual). Studies have emphasised the importance of routine symptom monitoring, as it improves patient outcomes, including health related quality of life and symptom control [38-40]. While the literature regarding monitoring symptoms focusses mostly on finding the most fitting tools for both clinicians and patients, our study showed that most clinicians identify patients' needs by picking up verbal and non-verbal ques. This emphasises that identifying and monitoring symptoms is a communicative process, in addition to using a tool or interpretating patient-reported outcomes.

The importance of clinicians' communicative sensitivity and demeanour when providing timely PC

Our study shows that it is necessary to be clear and sincere in order to have timely discussions about PC in daily clinical practice. While this sounds straightforward, it is actually a difficult skill that requires communicative tact and subtlety. Other studies have also illustrated this difficulty by stating that clinicians should be honest but hopeful [41] or honest without being rude [42].

Our findings show that timely PC integration requires sensitivity for picking up on patients' non-verbal cues and for exploring issues expressed non-verbally, for example by asking follow-up questions. Another qualitative study showed that non-verbal cues were one of the ways in which GP's recognise that their patients are worried, and how picking up on these cues can effectively reassure patients [43]. A grounded theory study stated that asking follow-up questions after verbal or non-verbal cues demonstrates empathetic listening, which makes patients feel heard and understood [41]. While this communicative sensitivity may come more natural to some clinicians than others, training and practice can improve active and empathic listening [44, 45].

Our study also found that patients appreciate a clinician who sees the person behind the disease and that patients were more likely to describe a clinician's attitude than their technical skills when asked what they appreciated in their treating physician. This is in line with what another study calls 'clinical demeanour', which is explained as the subjective assessment of a clinician's behaviour and one of the clinical attributes through which patients experience empathy [46]. While clinical demeanour is difficult to capture, it is essential for being perceived as personal and empathetic. There are many communication trainings, some with specific focus on cultivating empathy [47], although their effect on patients' outcomes remain unclear [48]. A proposition paper from the European Society of Medical Oncology that elaborates on clinicians' communicative tasks offers a possible explanation. It states that communication is more than a specific set of skills and requires constant judgement and interpretation of a patient's situation and context. To improve clinicians' competence and confidence, effective communication training should focus on clinicians' lived experience (their own feelings and attitudes) as well as society's discourse about cancer.

Strengths and limitations

A strength of this study is its inclusion of different perspectives, such as those of clinicians (both PC-generalist and PC-specialist), as well as those of patients, providing a comprehensive overview of the attitudes towards the timely integration of generalist and specialist PC. However, some limitations should be noted. First, clinicians were recruited through a contact person who was an oncology clinician, resulting in potential selection bias. To minimise bias, the researcher encouraged outreach to clinicians with less affinity with PC or who did not refer many patients to a PC consultants. Still, some PC-generalists expressed apprehension because they felt that they did not know enough about

PC. Therefore, this may have led to the inclusion of PC-generalists with more expertise than the average generalist. Similarly, patient recruitment through treating clinicians or PC consultants may have introduced selection bias due to ‘gatekeeping’, in which clinicians may select certain patients and exclude others [49]. To minimise the risk of bias, patients were recruited from different departments. Additionally, the varied perspectives, e.g. some patients preferring palliative care discussions soon after the diagnosis of incurable cancer, while others preferred focusing on treatment, were seen by the researchers as an indication of minimal bias. Another limitation is that patients can only reflect on their own disease trajectory, whereas clinicians can reflect on their practice based on a wide range of patients. Some patients found it difficult to identify the most appropriate time to discuss PC. We decided to merge the two coding trees to ensure a broad perspective on timely palliative care. Finally, the meaning of a term such as sincerity and what patients want to know about their illness and prognosis is largely influenced by a patients’ cultural background. This study predominantly included white Dutch patients who were aware of their diagnosis of incurable cancer. Thus, this study does not represent the cultural diversity of the Netherlands.

Conclusion

Timely PC in the care for patients with incurable cancer is individual and situational and therefore is not a one-size-fits-all approach. Tools such as the surprise question can support in timely integrating PC but timely PC depends on a patient’s individual context. Therefore, Finding the right time to integrate PC is a constant challenge and clinicians should be aware that timely PC is a constant search for the most fitting moment. It requires clinicians to frequently assess and interpret a patients’ situation and context. A proactive and gradual approach prevents clinicians from being too late and allows them to gauge how PC-related topics are received by the patient. Solid collaboration between different clinicians within the hospital allows for a more holistic view of patients and allows clinicians to easily call on each other’s expertise when needed. Patients appreciate tactful, sincere, and clear communication. These communicative tasks require clinicians to pick up on and respond to patients’ non-verbal cues and to have reflected on their own visions and lived experiences.

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Supplementary material 1: Topic list for clinicians

Introduction

Timely generalist palliative care

- How do you ensure palliative care is provided in a timely manner?
- How do you identify palliative care needs for your in- and outpatients? Do you or your colleagues use tools?
- How do you follow up on this identification?
- What is the added value of the way you provide generalist palliative care?
- When do you refer a patient to the specialist palliative care team?
- What an aspect of timely integration of palliative care that is not fully integrated but you would like to have realised in the future?
- What could other healthcare professionals or hospitals learn or adopt from your way of integrating palliative care?

Timely specialist palliative care

- What is the added value of involving the specialist palliative care team for achieving timely integration of palliative care?
- What makes the palliative care provided by a PC consultant team different from the palliative care provided by yourself or any other healthcare provider who is not a PC consultant?
- How does the specialist palliative care team complement generalist palliative care?
- What is the added value of the specialist palliative care team for certain patient groups (younger/older/determined diagnoses)?
- What barriers did you encounter in setting up and integrating the specialist palliative care team?
- What could other hospitals learn from the way your hospital has set up and integrated the specialist palliative care team?

Supplementary material 2: Topic list for patients

Introduction

Illness trajectory

- Can you tell something about your illness trajectory?
    - Diagnosis, treatment trajectory, how patient found out their cancer is incurable

Relationship with clinicians

- How often do you see your treating physician/case manager*/oncology nurse*?
- How do you experience the contact with your treating physician/case manager*/oncology nurse*?

Topics discussed during consultation clinicians

- What topics do you discuss when you see your treating physician/case manager*/oncology nurse*?
- Are other topics discussed besides treatment?
- Does your treating physician/case manager*/oncology nurse* pay (enough) attention to your needs?
    - Needs on the physical, psychological, social and spiritual dimension
- How are these needs addressed?

Timely identification of PC needs

Palliative care is all care aimed at preserving and, if possible, improving the quality of life of someone with incurable cancer or other life-threatening illness or frailty and their families. Timely integration of palliative care is very important, as it leads to a better quality of life; people can make their personal choices in time and keep more energy for things that matter to them most. Therefore, it is important that clinicians recognise that patients have issues or questions on the physical, psychological, social or spiritual domain.

- When was it clear to you that your illness is incurable?
- Have you, since then, spoken to a clinician about your care wishes and needs (on the physical, psychological, social and spiritual dimension)?
    - If so, with whom?

- When was the first time you a clinician about your care wishes and needs (on the physical, psychological, social and spiritual dimension)?
- According to you, when is the right time to discuss care wishes and needs (on the physical, psychological, social and spiritual dimension) for the first time?

Advance care planning

During advance care planning discussions, your healthcare provider talks to you (and your family) about your possible illness trajectory, your wishes, values, needs and preferences for future treatments and care.

- Have you conducted advance care planning discussions with a clinician?
- If so, when was the first time? With whom? What did you discuss?
- According to you, when is the timely moment to start these discussions?

Routine symptom monitoring

Monitoring symptoms, needs and quality of life of patients with an incurable disease can provide a starting point to engage in a conversation about values, wishes, needs for the remaining time.

- What issues are you struggling with?
  - Issues on the physical, psychological, social and spiritual domain
- Are you frequently asked about your issues?
  - How often, in wat way and by whom?
- When was did they start with monitoring your issues, needs and quality of life?

Involving the specialist palliative care team

Every hospital providing cancer care has a specialist palliative care team. This team consists of clinicians from different disciplines, all with experience or expertise in providing palliative care. Together with you and your family, they identify problems, wishes, needs and possibilities. They can support you and family with emotional problems such as fear, sadness, and loneliness, questions about meaning of life and treatment wishes and boundaries. They can also provide you and family with good explanations and information on end-of-life care, for example on illness, palliative sedation, euthanasia, the dying phase and care options in hospital, at home, hospice or other care institutions.

- Did you know about the specialist palliative care team?
- Who informed you about the specialist palliative care team?
- When were you informed?
- What did you think of this timing?
- Have you had a consultation with a palliative care consultant?
  - If so: when was the first time?
  - What do you think about the timing?
  - How do these conversations differ from the conversations you have with other clinicians?

* Questions were added after pilot-test with patients (n=2)

Supplementary table 1 Textbox: themes, category and quotes

	Theme	Category	Perspective	Quotes
How the concept of 'timely PC' is understood by oncology clinicians and patients with incurable cancer	Timely PC is individual and situational	Different moments in the disease trajectory	Clinician	Receiving the message that you are not going to get better could already be the moment of introducing palliative care, but I am very aware that that might be too black and white. (Medical oncologist and consultant of the SPCT)
			Clinician	With those people [who supress emotions and are not open] I like to have a reason for discussing PC, so you have a reason to ask follow-up questions. Sometimes that can be at the beginning but it can also be that you have already had one or two lines of treatment. (Oncology nurse practitioner)
			Patient	I definitely think that I will need some time to process it when I am then told that the immunotherapy will stop and that I will not be able to receive chemo. I will wonder whether have I made the right choice. At that time I will need help.
			Patient	The right moment for me would have been when you start your treatment. At that point in time so much is happening around you that influences your disease trajectory. So actually when you just started treatment, because it is nice to have some support after you have heard your diagnosis.
		Patients coping and attitude	Clinician	We have a patient who does not want anything besides his curtains being closed. You can give him a lot of advice but at a certain point you realise that that is how he does it at home as well. So we have to let go, otherwise it is very annoying for both parties. So we try to provide the care we think is good for him, and if he says he wants to be left alone for everything else, you have to accept that. (Oncology nurse)
			Clinician	When I see people for the first time and they say 'well, this is what I think and how I feel about it', and are very open about it, then it can be discussed right away. These are patients that have often already discussed it with their family. And the conversation can still be sad, but they do not experience it as a barrier or as a bottleneck. It is more difficult with people who hide it away or block it out. That makes it much harder to find out how someone feels about it. (Oncology nurse practitioner)
		Involving a PC specialist	Clinician	It is easy to say: all patients with a certain diagnosis will receive palliative care, and it becoming a checklist. But in daily clinical practice you have to identify and assess who needs it and when they need it. I find it difficult to define who that is. Because I just mentioned migration background, but of course there are a lot of people with a migration background who do not need specialist palliative care. But the combination of a limited network, cultural barrier, language barrier, and the illness behaving aggressively, or having a lot of complaints right from the start, can make you decide that a person should be referred to the SPCT. (Medical oncologist)

Supplementary table 1 Continued

Theme	Category	Perspective	Quotes
		Clinician	(…) when it becomes complex for example when multiple disciplines are involved, when a patient does not really have illness insight or does not want to have it, or when their perspectives on illness insight differs from their families' perspectives very much. So when things are just not as easy. (Oncology nurse practitioner)
	Having specific symptoms or needs	Patients	I think she [physician assistant] had a good sense, because of course she also saw I was doing better and kept on doing better and better, but the question 'for how long' remained. In the beginning they said you will die of this disease but they did not give a time frame.
		Patient	This was the right time because I was really afraid of choking.
	(Still) feeling well	Patient	I do not feel the need to talk about possible future scenario's. because I am still feeling good. I do not know what would be the right moment for me to do discuss those things.
		Patient	For me it was timely because I still felt well enough, mentally and physically to be able to [discuss care wishes and care boundaries].
Identifying the right time is an ongoing challenge	Too late	Clinician	Being timely applies to the whole treatment trajectory, or being timely enough that you still have opportunities to be able to integrate it properly. That you are not playing catch-up for instance when people have symptoms before you have even been able to start the conversation. (Oncology nurse practitioner)
		Clinician	Other fields than oncology mainly involve us [the SPCT] when there is a crisis, so then you are actually already a few steps too late, which sounds negative, but it is just not timely. (Oncology nurse practitioner and consultant of the SPCT)
	Too early	Clinician	It is very useful to talk to patients in an early stage about their thoughts and feelings about the end of life and what they have already organised for that phase. However, it also very much depends on how certain treatments will work out and in terms of side effects and things like that. With some patients talking about it too early was not received well. (Pulmonologist)
	Too early	Patient	Not right away, because in the beginning you are so shocked and so much is happening at once. I also thought that [my diagnosis] meant I was going to die so that meant that there was no need to discuss anything anymore because when it is done it is done. But after six months you think, gosh, I'm still here, let me think about what's going on and what is coming my way. Maybe being timely is very individual, when you yourself are ready, something like that.

Supplementary table 1 Continued

Theme	Category	Perspective	Quotes
Proactive care is essential	Looking ahead	Clinician	I make people very aware that technically there is always an immunotherapy available, but is that what you want? Do you want to come to the hospital that often? What do you gain? (...) I want to manage their expectations so they do not think that they can happily go on for another six months as long as they get another shot or pill, but to emphasise that everything has a consequence. (Haematologist)
		Clinician	Of course you have the surprise question of a life expectancy of one year, I find that a nice tool because it gives a guideline, but I also think it is good to have those conversations with people who have a life expectancy of 3 years (Medical oncologist and consultant of the SPCT)
	Gradual process	Clinician	In the beginning you are very busy explaining their diagnosis and what we can do to make them feel better. During the course of the treatment, once the initial storm has passed, more questions tend to arise. So it is gradual, it is not one moment. (Haematologist)
		Clinician	I really just try to call it by its name and that often leads to a conversation. And when then we talk about it, each time I check which part we should discuss. (...) I have usually been feeling someone out before I ask them if they still want to go to the hospital when they become very sick while their wish is to die at home. Every time I take a part of ACP but I am not going through the whole ACP check list. Sometimes I discuss this, sometimes something else. And then I also let it rest it for a while. And then you keep checking if there are needs and then you bring it up again. (Medical oncologist and consultant of the SPCT)
		Clinician	I try to decide for myself what I want to know and what is important for the overall picture so I know what kind of help is needed. So I pick a few focal points, either in advance or during the conversation with the patient, such as knowing about the home situation, getting a sense of the social network they can fall back on, the physical or psychological issues someone has. (...) And if you find that you need more time, I will tell someone that there is so much to discuss that it is a good idea to continue the conversation at a later time. (Oncology nurse and case manager)
	Prioritising	Clinician	When you hear a patient say something which is more psychosocial you can say that it is very important but that you are not the right person for those issues. But that you can bring them into contact with a spiritual carer or our social worker. This shows them that you have heard them and that what they said is worth paying attention to. But you don’t have to do it [caring for a patient] all by yourself. (Medical oncologist and consultant of the SPCT)

Supplementary table 1 Continued

	Theme	Category	Perspective	Quotes
How PC is provided in a timely manner in daily clinical practice	Strong collaboration among various clinicians	Working together with other disciplines	Clinician	At the outpatient clinic for lung oncology patients we have a team consisting of a pulmonologist, pulmonary nurses and doctor's assistants. The pulmonary oncology nurse plays an active and important role in recognising palliative care needs and addressing and discussing them with all dimensions involved, not just somatic. I think differs from the clinic, where the nurses are a bit more [PC] generalists, while the pulmonary oncology nurses here are already very focused on that [PC]. (Pulmonologist)
		Physicians on collaboration with nurses	Clinician	I think it is especially useful to increasingly train the pulmonary oncology nurses in order to get the basic level of the pulmonary oncology nurses in the field of palliative care higher and higher, so that you can very easily approach the regular pulmonary oncology nurse and that you can provide that good palliative care in a low-threshold way. (Pulmonologist)
		Skillset of nurses	Clinician	I often say that I wish people would give some space to the things they are afraid of, think about the future or allow the sadness. Because I notice that when they do so, peace and control returns. Last week I saw a lady who was not doing so well physically, and who has a partner, and it seems that he finds that very difficult, but do not seem to find each other in that. So I said I would really like it if you could talk to someone about it, also because it gives you more control over the situation, what do you want, what do you not want? What can you expect? What can you expect of the caregiver you have the conversation with? I always try it to give people back control and also to connect with the way people want to live life. (Oncology nurse and case manager)
		Collaborating with the SPCT	Clinician	It is important that the lines of communication [between PC-generalists and the SPCT] are short. I think that the way we do it is also due to the fact that we collaborate very well. We speak each other's language, we know how to find each other. If one person takes over from someone else we know that it is not because the other cannot do it, but it is because it is more fitting for the other person to do it. (Medical oncologist)
			Clinician	They [the SPCT] have a multidisciplinary consultation meetings in which the patients are discussed. It is a very nice group of people, things can be discussed properly and there is also room for nurses to share their stories about the conversations they had with the patient. So it is a safe environment and everyone is approachable. (Oncology nurse practitioner)
	Having the courage to start a clear and sincere conversation	Being mindful of using the right words	Clinician	I always try to say it, meaning really calling it 'death'. Or I will ask if someone is afraid of their last stage of life, of dying? I try to really just call it by its name. And often that starts a conversation. (Medical oncologist and consultant of the SPCT)

Supplementary table 1 Continued

Theme	Category	Perspective	Quotes
		Clinician	I do think conversation techniques can be useful for it [providing generalist PC], because it does often really come down to words. How you name it and how you frame it influences how people respond to it and how open they are to it. (Pulmonologist)
		Patient	He said it is lung cancer with a lot of metastases. So we asked what options we had to which he said “if there are any options left at all”. Later that afternoon we had an appointment with the pulmonologist and instead of him saying that we could discuss our options with the pulmonologist, that’s what he said. (…) I know he has to say something, but he should have said it in a more subtle way.
	Being sincere yet subtle	Patient	He did not say that I would not get better, he just said you have metastatic cancer. Well then you know, because you realise having metastatic cancer means that you are not going to get better.
		Patient	It was a very good conversation (…) he was straightforward but he also monitored whether I could take it. He said ‘I am just careful, to see what you can handle’. I told him that I can handle pretty much so that he could just say it.
	Clear explanation of PC	Patient	You always have to explain what palliative care is. Just explain that in the hospital there we also provide palliative care.
Being sensitive and personal	Picking up on verbal and non-verbal cues	Clinician	For example if people are very insecure, constantly seeking confirmation, seeking something to hold on to. (…) It could be that people have physical complaints that we cannot quite put our fingers on, that someone seems stressed. Sometimes people mention it themselves that they feel the need to discuss certain topics. As a caregiver I feel you have a very important role in daring to ask follow-up questions. (Oncology nurse)
	Asking follow-up questions	Clinician	We always ask [new patients] how they are coping and how they are doing mentally. If patients have received bad news I always inform about their mental state. With other patients I do not always ask about their mental state but sometimes I sense something so then I ask them how they are doing mentally and whether they need help. (Oncology nurse)
		Patient	When you get to radiology and take part in a an experimental treatment, there are a lot of really super-specialists. They are all extremely handy with the equipment and extremely skilled, they just cannot deal with people.
		Patient	Sometimes I also look at her and I see in her eyes that she must have had a rough day. And when you ask you right away get to hear what she has been through. I like that, that the conversation is a two-way street.

CHAPTER 4

Clinicians' experiences, perspectives, barriers, and facilitators of integrating palliative care into haematological cancer care: a qualitative interview study

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Abstract

Purpose Palliative care is integrated into haematological malignancy care less frequently than in the care for patients with solid tumours. Therefore, this study aimed to better understand the perspectives and experiences of clinicians regarding integrating palliative care for patients with haematological malignancies.

Methods Interviews were conducted with clinicians who care for haematological patients. The interviews were analysed using thematic analysis.

Results Participants acknowledged the importance of integrating palliative care. However, they noted that patients with haematological malignancies often have a more unpredictable disease course than patients with solid tumours. Unpredictability and the potential for rapid deterioration were identified as main barriers to the integration of palliative care. In addition, participants indicated that the availability of multiple treatment options may result in a tendency to prioritize these treatments over integrating palliative care. The participants recommended that palliative care should have a prominent position in the haematology curriculum and suggested that including palliative care topics in conferences could enhance awareness.

Conclusions To integrate palliative care into haematological malignancy care, it is necessary to enhance the knowledge and awareness of palliative care among haematological clinicians. A two-track approach, where both curative and palliative pathways coexist, could facilitate the integration of palliative care.

Introduction

Worldwide cancer is a leading cause of death and a significant impediment to life expectancy [1]. It is estimated that there will be approximately 28.4 million new cases of cancer worldwide in 2040, representing a 47% increase from the 19.3 million cases recorded in 2020 [2]. Consequently, there will be an increased demand for palliative care services and a need to improve the integration of such care into standard oncology care [2,3]. The World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of patients and their families facing challenges whether physical, psychological, social or spiritual associated with life-threatening illness" [4]. The importance of integrating palliative care services into oncology care is widely acknowledged [5-7]. A body of evidence suggests that palliative care can benefit cancer patients and their loved ones in several ways, including improving their quality of life, reducing symptom burden, preventing inappropriate end-of-life care, increasing satisfaction with care, and improving caregiver outcomes [5,7-8].

Haematological malignancies constituted the fifth most frequently diagnosed type of cancer in the Netherlands. The incidence has doubled in the last 25 years and the mortality rate in the Netherlands was 3.956 [9]. Haematological malignancies are characterized by a heterogeneous disease course and potential for curability, with disease progression being unpredictable and potentially deteriorating rapidly at the end of life [10]. These factors may contribute to the complexity of providing timely palliative care for patients with haematological malignancies [11].

Patients diagnosed with haematological malignancies receive palliative care less frequently and at a later stage of their disease than patients with solid tumours [14]. Nonetheless, these patients experience a physical and psychological symptom burden that is comparable to that of patients with advanced solid tumours [15]. Patients with haematological malignancies had less advance care planning conversations, were less likely to be referred to a specialist palliative care team (SPCT) and were more likely to receive care on the intensive care unit in the last 30 days of life [16, 17]. Clearly, the integration of palliative care into haematological oncology is still lagging behind [12,13]. Therefore, this study aimed to gain a deeper understanding of the perspectives and experiences of hospital clinicians regarding the provision of palliative care to patients with haematological malignancies, and to identify the barriers and facilitators they perceive in integrating palliative care into standard haematological malignancy care.

Methods

Study design and setting

Semi-structured interviews were conducted to gain insight into the experiences, perspectives, barriers, and facilitators of clinicians regarding the integration of palliative care into haematological malignancy care in the Netherlands. In the Netherlands, an integrated generalist and specialist palliative care model is used [18], in which all health professionals should be prepared and adequately 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. The Consolidated criteria for Reporting Qualitative research (COREQ) checklist was used for reporting [19].

Study population

Convenience sampling was used to recruit clinicians experienced in treating patients with haematological malignancies. The participants were recruited primarily through the network of the Netherlands Comprehensive Cancer Organization (IKNL) and via social media. Individuals were invited to contact the researcher (B.M.B) via email to request further information regarding the content and purpose of the study. Clinicians were eligible to participate if they worked in a hospital in the Netherlands, cared for haematological patients, and were older than 18 years. To obtain a broad range of perspectives and experiences, clinicians working at different types of hospitals, including academic hospitals, top clinical teaching hospitals and general hospitals, were included.

Data collection

In-person interviews were conducted in March and April 2024 in private rooms within the hospitals where the participants were employed, until data saturation was reached. The mean duration of these interviews was 45 minutes. A summary of topics and questions was used as interview guide, which was developed using existing literature and the expertise of researchers and clinicians. The guide consisted of the following topics: descriptive information, perspectives and experiences of integrating palliative care into haematological malignancy care, added value of integrating palliative care into haematological malignancy care and barriers and facilitators in the integration of palliative care. Furthermore, participants were asked to complete a short questionnaire in order to collect socio-demographic data, including age, gender, current occupational role, type of hospital where the participant was employed, years of work experience in healthcare, years employed in the current position and training in palliative care (Table 1). All interviews were conducted, audio recorded, transcribed verbatim and supplemented with field notes during and after the interview by one researcher (B.M.B). The process of data collection and analysis was cyclical, with constant comparison. The final version of the interview guide is presented in Supplement 1.

Data analysis

The interview transcripts were analysed using thematic analysis, based on the six phases described by Braun and Clarke [20]. Data familiarization involved reading and rereading the transcripts in preparation for coding. The data were then coded systematically and inductively by two independent researchers (B.M.B. and L.B.) to establish interobserver reliability and discussed with a third researcher (H.P.). The use of a constant comparative method within and across interviews enabled the identification of recurrent patterns or themes. Subsequently, these were interpreted through the exploration of meaning and connections. Multiple rounds of coding and an active search for deviant cases refined the themes, resulting in a comprehensive understanding of clinicians' perspectives, experiences, barriers, and facilitators. Quotes were used to illustrate the emerging themes. ATLAS.ti software version 24.1.1., a qualitative analysis package, was used for thematic analysis of the data [21].

Results

A total of 16 clinicians were interviewed. The mean age of the participants was 49 years (range: 34-75), with a mean working experience of 15 years in their current position (range: 3-40) (Table 1).

Table 1 Sociodemographic characteristics of participants (n=16)

Profession	**n**
Haematologist	7
Hospital physician haematology	1
Physician assistant haematology	1
Haematology nurse specialist	4
Haemato-oncology nurse	2
Palliative care nurse specialist	1
Gender	**n**
Female	11
Age (mean, range)	49 (34-75)
Type of hospital	**n**
Academic hospital	7
Top clinical teaching hospital	7
General hospital	2
Training in palliative care [1]	**n**
Yes	10
Years of work experience in current position, (mean, range)	15 (3-40)
Years of work experience in healthcare, (mean, range)	21 (10-42)

[1] Training included for physicians: 2-year palliative care continuing medical education, 8-day course in palliative care and basic palliative care training. Training included for nurses: 1-year continuing nursing education, 8-day course in palliative care and continuing nursing education for oncology.

Four themes were identified: perspectives on integrating palliative care in haematological malignancy care; barriers due to characteristics of haematological malignancy; barriers due to attitudes and beliefs; and facilitators to enhance the integration of palliative care (Table 2).

Table 2 Subthemes and quotes per theme

Perspectives on integrating palliative care in haematological malignancy care	
Subthemes	**Quotes**
The added value of palliative care into haematological care	"For me, palliative care, is about ensuring quality of life until death. Very often this last phase is somewhat overlooked or not discussed enough, but you can still provide a lot of quality even if you can't cure. You start to talk about other things that can bring someone comfort or happiness, rather than focusing on treatments that aim to cure. That's what I find beautiful about palliative care. How do you say it? It's about looking at quality in a different way." - Hospital Physician haematology
The pivotal role of specialist palliative care teams in the care of patients with haematological malignancies	"They (SPCT) ask about what matters most in the last moments, family relationships, faith and spiritual care. They look at a much bigger picture than just the diagnosis. I know the patient and what is important to them, but they look at much more than that." - Haematology nurse practitioner

Table 2 Continued

	"Collaboration with the specialist palliative care team becomes problematic when there is overlap and interference with medical management. For example, if they start saying that a certain therapy has a low chance of success and advise against, or if we've already made a pain management plan and the palliative care team gives the patient different advice." - Haematologist
	"I find the palliative care team here at the hospital very supportive and approachable, and we have been able to reach out to them more and more. But sometimes it is still at the very end." - Hospital physician haematology
Barriers due to characteristics of haematological malignancy	
Subthemes	**Quotes**
The unpredictable course of disease and rapid deterioration	"The unpredictability of the disease further complicates the situation. For example, if the disease recurs and is no longer treatable, it often progresses rapidly. In contrast to some solid malignancies, where you can weigh up treatment options and consider palliative care that might prolong the patient's life for another year and a half, in our case it's just a matter of weeks. Some patients die within a week of the discussion." - Haematologist
	"One of the challenges in haematology is that the prognosis is difficult to predict and there are many complications. Patients can also suddenly develop an infection that is hard to treat and can lead to unexpected deaths. It's always uncertain whether someone will survive such an infection. Unexpected events can always happen in haematology." - Haematology nurse practitioner
The lack of a clear starting point for palliative care in haematological malignancy care	"Timely initiation of palliative care is a challenge because it is difficult to determine within haematology. When I first came to the hospital, I was told that palliative care didn't exist in haematology. Everyone can be treated with curative intent initially, which creates a difficult tension. In solid oncology, many patients are diagnosed with metastatic disease, and you know, even if it's ten years, they're going to die of it eventually. So, the whole treatment plan is already focused on palliation and prolonging life. In contrast, almost everyone in haematology can be treated with curative intent, although not everyone will be cured. This makes it very difficult to determine when to introduce palliative care." - Hospital physician haematology
	"I find it difficult to create a specific care pathway for haematological cancers. For example, first, you receive the diagnosis, then you start treatment, and in week seven week you should have a conversation about palliative care. And, something always happens with haematology patients. They often end up here (hospital) because of a complication, which makes it impractical to have such conversations calmly at that time." - Haematologist
The multitude of treatment options discourages consideration of palliative care	"In oncology, you often have a longer trajectory where you can already see it coming. So, you start with palliative chemotherapy, which works for a while and then it doesn't. So, it should be similar in that sense. However, in haematology we are often still on a curative path. For example, with AML, if you're in remission and you follow up with a DLI, you still have a 30 to 40 percent chance of a cure. And a cure is a cure. It means living longer. Oncology can't offer that." - Haematologist
	"Patients often receive a diagnosis out of the blue and start their treatment right away. There's a lot of information to process and sometimes there's no time to discuss what to do if things don't go well. It's hard to find the space for that, although it's important. Because the train of haematology treatments keeps moving, there's rarely a pause to consider palliative care or to accept that things might take a different turn." - Haematology nurse practitioner

Table 2 Continued

Barriers due to attitudes and beliefs	
Subthemes	**Quotes**
Holding on to hope and its necessity for enduring the intensive treatments	“It’s also about hope that you don’t want to take away from them (patients). This makes it difficult because a patient might feel that you (healthcare professional) are already being negative by discussing what could go wrong. You don’t want to take away their hope.” - Haematology nurse practitioner
The difficulty of discussing palliative care for clinicians	“Sometimes, it’s easier to offer another treatment rather than to have the difficult conversation about where the patient wants to die or how they envision the final phase. Sometimes, there isn’t enough time for these discussions, or people find them difficult. In these cases, it can be more convenient to offer to try another treatment instead.”- haematologist
Facilitators to enhance the integration of palliative care	
Subthemes	**Quotes**
Increasing awareness and knowledge of palliative care in haematology	“I think it’s all about explaining. That applies to a lot of things. I explain to many patients that I use the term palliative care, and then I clarify that it doesn’t mean terminal, but that people often live for many years. So, it’s just a matter of explaining to the individual patient what you mean.” – Haematologist
	“Attention to palliative care is growing, but when I attend my oncology conferences, palliative care and the option not to treat are very prominent. At haematology conferences, however, it remains a neglected topic, with the focus primarily on treatment options.” – Haematologist
Implementation of a two-track approach can support palliative care integration	“A two-track approach will help. I think it’s particularly beneficial for haematology. It allows hope to be maintained, which we know is crucial and is supported by research. So, with this two-track approach hope can be sustained. But at the same time, it’s important to prepare for the possibility that things may not go as planned and to think about what is essential, including the quality of life in the present moment.” – Palliative care nurse practitioner

Perspectives on integrating palliative care in haematological malignancy care

The added value of palliative care into haematological care

The participants identified improvement of quality of life as the primary added value of palliative care for patients with haematological malignancies. Participants emphasized that palliative care provides a peaceful space that allows patients to focus their energy on intensive medical treatments. The importance of preparing patients for potential complications at the end of life and of discussing the wishes of patients and their loved ones as an integral aspect of haematological care was also underlined.

The pivotal role of specialist palliative care teams

Participants reported that they involved the SPCT when dealing with complex cases, such as instances of uncontrollable pain. They stated that the SPCT was seen as an additional component to the general palliative care they provided. Participants indicated that they found it valuable that the SPCT looked at the patient from a different perspective, thereby providing a broader understanding of the patient and offering insights that may not be apparent to the haematologist. Such insights included, for instance, spiritual wishes related to the end of life. Additionally, it was noted that patients may disclose more information to an external healthcare professional from the SPCT than to their haematologist.

Participants also reflected on the difficulties and challenges with involving the SPCT. A clear delineation of roles was essential, according to the participants, and they preferred the SPCT in a more supportive role and not being (too) involved in medical decisions. Some of the nurse specialists working in the haematology outpatient clinic indicated that they were less likely to involve the SPCT, citing that they were managing the palliative care themselves and often had a long-standing care relationship with the patient. In addition, participants indicated that patients did not always appreciate the involvement of another healthcare professional at this stage.

Barriers related to characteristics of haematological malignancy

The unpredictable course of disease and rapid deterioration

Participants noted that patients with haematological malignancies often have a more unpredictable disease course than patients with solid tumours. The disease course can vary from long periods of stability to a sudden decline and sometimes leading to death within days of diagnosis. Therefore, the goal of treatment can suddenly and unexpectedly shift from a primary focus on cure to discussions about impending end of life. These were identified as important barriers to the integration of palliative care for patients with haematological malignancies.

The lack of a clear starting point for palliative care

Given the inherently unpredictable nature of haematological malignancies, participants expressed they found it difficult to identify the optimal time to initiate palliative care discussions. This difficulty is further compounded by the initial curative intent for many patients with haematological malignancies.

Participants noted that there is no clear, universally accepted point at which palliative care should be initiated. Furthermore, due to the variable course of haematological malignancy the moment at which clinicians integrate palliative care differed considerably, varying from the moment of diagnosis to the point where no further treatments options are available. The unexpected and rapid deterioration was mentioned as a reason for having insufficient time to initiate palliative care discussions or to involve the SPCT.

The multitude of treatment options discourages consideration of palliative care

Participants acknowledged that many patients with haematological malignancies have access to a wide range of treatment options with a high potential for cure. Most participants expressed that the availability of multiple treatment options and the high potential for cure may result in a tendency to prioritize these treatments over integrating palliative care. The clinicians' primary focus on the treatments hinders their ability to engage in palliative care conversations.

Participants also noted that, in their experience, patients with haematological malignancies are often not mentally receptive to palliative care. This may be due to the numerous intensive treatments they undergo and the focus placed on these treatments. Moreover, during the course of these treatments, according to the participants, both the patient and the clinician find themselves lacking sufficient opportunity to discuss palliative care.

Barriers due to attitudes and beliefs

Holding on to hope

Participants expressed their concern that initiating a discussion about palliative care may diminish patients' hope. The participants noted that patients have the desire to maintain hope, as this is essential for them to endure the rigors of intensive treatments for haematological malignancy. Furthermore, since most patients with haematological malignancies have access to potentially curative treatments, each new treatment offers a new opportunity for hope.

However, participants acknowledged that the need to maintain the patient's hope creates a conflict with the need to discuss palliative care, which needs to be addressed in order to ensure the best possible care for the patient.

The difficulty of discussing palliative care for clinicians

Clinicians indicated that it is easier for them to discuss potential treatment options and the likelihood of a cure than to discuss palliative care, resulting in a predominant focus on the prospect of a cure. Conversations about palliative care were sometimes described as a source of tension and discomfort for clinicians. An underlying reason for this discomfort is that palliative care discussions tend to raise difficult questions, particularly those related to prognosis. Due to the unpredictable nature of haematological prognosis, clinicians may be reluctant to provide definitive responses. The discomfort is further compounded by the fact that the curriculum for haematology fellows does not adequately equip them with the required skills to provide palliative care.

Facilitators to enhance the integration of palliative care

Increasing awareness and knowledge of palliative care in haematology

Participants suggested that palliative care should become a prominent part of the haematology curriculum to increase knowledge about palliative care. Participants acknowledged the importance of giving patients a clear and accurate explanation of palliative care. This will help to avoid the misconception that palliative care is only for the terminally ill and to ensure that patients' hopes and optimism are not inadvertently undermined.

It was acknowledged by participants that there is a necessity for greater awareness of palliative care in the treatment of haematological malignancies. It is recommended that awareness and knowledge of palliative care can be enhanced by facilitating discussions at conferences for hematologists.

Implementation of a two-track approach can support palliative care integration

Some participants indicated that a two-track approach could help to integrate palliative care into haematological malignancy care. This two-track approach means that the curative and palliative care pathway coexist, allowing for the possibility of a cure while simultaneously integrating palliative care. In a two-track approach hope is maintained and disease-oriented treatment continued. At the same time, patients with haematological malignancies are prepared for the potential complications or an acute, unexpected course of the disease.

Discussion

We found that clinicians working in haematological oncology recognized the added value of integrating palliative care into haematological malignancy care. Several barriers were also identified. These barriers included specific characteristics of haematological malignancy, such as the unpredictable course of the disease, and attitudinal and belief barriers, such as the perceived difficulty of initiating discussions about palliative care. Increased awareness and more knowledge of palliative care in haematological malignancy care and a two-track approach were seen as important facilitators and strategies to integrate palliative care into haematological malignancy care.

First, our study shows that clinicians recognize the added value of palliative care. These findings are consistent with previous studies on the integration of palliative care into usual haematological care [8,22,23]. For example, Giusti et al. [24] found that patients diagnosed with multiple myeloma who received early palliative care experienced numerous benefits, including improved pain management. However, it is notable that the perceived value of palliative care is comparable to that in solid oncology. Therefore, the rationale for implementing palliative care is not fundamentally different between solid oncology and haematology [25]. Our results showed that participants perceive SPCTs as a valuable addition to their general palliative care provision and acknowledge that collaboration with SPCTs has increased in recent years. However, a clear delineation of roles is crucial, with a preference for the SPCT not to be overly involved in medical decisions and to act in a more supportive role. According to McCaughen et al. [26], palliative care specialists described that the end-of-life needs of haematological patients can be met by the haematological team, particularly the clinical nurse specialist. The findings of the current study indicate that haematology nurse specialists do not consistently perceive the involvement of another healthcare professional from the SPCT necessary for their patients. However, in case of complexity, haematology nurse specialists found the input of the SPCT beneficial. Nonetheless, several studies have confirmed that referral to the SPCT by a haematology team often occurs late in the course of the disease [26,27].

Second, participants emphasize that patients with haematological malignancies often have a more unpredictable disease course than patients with solid cancer. As a result, treatment goals can shift abruptly from a primary focus on cure to discussions about end-of-life care. This unpredictability and rapid deterioration have also been identified as a significant barrier to the integration of palliative care in other studies [10,11]. Although the lack of a clear starting point for palliative care and the difficulties of prognostication have been identified as barriers to its integration, a two-track approach, in which curative and palliative care pathways coexist is seen as a significant facilitator. This indicates that the identified barriers do not preclude the possibility or necessity of integrating palliative care for patients with haematological malignancies. Rather than hindering the integration of palliative care, the unpredictability and rapid deterioration of haematological malignancies should encourage advance care planning and discussions about palliative care, thereby ensuring that patients are adequately prepared for sudden changes. Verhoef et al. [28] similarly proposed a two-track approach, particularly for patients with haematological malignancies, to ensure the timely integration of palliative care. An integrated approach has also been proposed in cases of chronic advanced heart failure and chronic obstructive pulmonary disease (COPD), where similar difficulties, including the unpredictability of the disease course, have been reported [29,30]. To address these challenges and provide optimal care for patients with cardiovascular disease, a set of guiding principles has been developed. These include the integration of palliative care alongside specialist cardiovascular care [31].

Third, our findings show a reluctance to discuss palliative care due to the predominant focus on cure and the perceived ease of discussing potential treatments. There is also a concern that discussing palliative care may deprive patients of hope, as hope plays a pivotal role in enduring intensive treatments and any new treatment available is seen as a potential source of hope. This is consistent with the findings of Dowling et al. [32], who also indicated that haematologists' hope of cure results in many patients with haematological malignancies being actively treated until the end of life. However, Cohen et al. [33]

found that there was no association between advance care planning, including discussion of end-of-life issues, and decreased patient hope. Furthermore, they showed that hope was even higher in patients who had palliative care discussions than in those without. They therefore pleaded for palliative care discussions and for clinicians not to hesitate to have them. The study by Olsman et al. [34] posits that healthcare professionals can incorporate different forms of hope, which facilitates communication and does not preclude honest discussions about prognosis or goals of care, which can lead to a better quality of care [34,35]. Some participants expressed discomfort when discussing palliative care with their patients, with such conversations being a source of tension and unease for clinicians. It is crucial for clinicians to recognize their own discomfort and limitations in palliative care, and to involve the SPCT promptly when needed.

Strengths and limitations

Participants of this study included clinicians who have received additional training and experience in palliative care, as well as those who have not received such training and have less experience in palliative care. Including both the perspective of generalist and specialist palliative care provides a comprehensive overview of the challenges and attitudes to palliative care. A limitation of the study is the method of participant recruitment, convenience sampling. As participants were recruited through the network of IKNL and via social media promotion, it is possible that those who responded were primarily healthcare professionals with an affinity for palliative care and resulted in self-selection bias. This might select for participants more open to discussing palliative care with their patients in their daily work, or are already effectively integrating palliative care, resulting in the overrepresentation of opinions and perspectives of those open to palliative care for this patient population. Nevertheless, several barriers emerged from the analysis, suggesting that the results may underestimate the problems. Moreover, future research is needed to get insights in the daily practice of care for these patients at the end of life, including defining quality of care in end-of-life care for patients with haematological cancer. Furthermore, because data regarding palliative care are very scare in patients with haematological cancer, more insights into the patients' perspective on palliative care and on the daily practice of providing palliative care to these patients is needed

Conclusion

This study provides insight into the complexity of care for patients with haematological malignancies and the challenges their clinicians face in integrating palliative care into haematological malignancy care. For optimal integration, it is necessary to enhance the knowledge and awareness of palliative care among all haematological clinicians. A two-track approach, where both curative and palliative pathways coexist, could facilitate the integration of palliative care into haematological cancer care.

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CHAPTER 5

Timely integration of palliative care into oncology in hospitals in the Netherlands: a mixed methods feasibility study

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Abstract

Background Timely integration of palliative care has numerous benefits for patients with incurable cancer. Based on a recent national Delphi study on the timely integration of palliative care in oncology, three recommendations were formulated regarding 1) advance care planning (ACP), 2) routine symptom monitoring during the last year of life, and 3) involving the Specialist Palliative Care Team (SPCT) during the last three months of life. This pilot study aimed to assess the feasibility of these recommendations in the Dutch context.

Methods Four Dutch hospitals implemented these recommendations for three months. Feasibility was assessed in three ways. First, the extent to which the recommendations were applied was assessed by analysis of electronic medical records (EMRs) of 542 patients with incurable cancer. Second, the extent to which clinicians (n=27) found the recommendations applicable was assessed using a questionnaire including the Measurement Instrument for Determinants of Innovations (MIDI) and self-administrated questions. Last, patients' experiences (n=70) were assessed using the EORTC IN-PATSAT and self-administrated questions regarding using the recommendations.

Results The recommendation on ACP was applied in 49% of eligible patients and the recommendation on symptom monitoring and SPCT in 58%. Most clinicians agreed that all three recommendations were important to achieve timely integration of palliative care (85%). The majority reported being able to conduct ACP discussions (78%), to consider involving the SCPT in case of complexity (73%), and to offer SPCT consultation in case of a life expectancy of ≤ 3 months (68%). A minority reported being able to pay attention to symptom monitoring across the four dimensions (42%) and to record outcomes in the EMR (19%). Patients who received care according to the recommendations were equally satisfied with care compared to those who received standard care, except when symptoms of social problems were monitored; these patients were more satisfied with care, respectively 83.1(SD 18.7) vs 71.2(SD 20.1).

Conclusions Implementing the recommendations on timely integration of palliative care in daily clinical oncology practice seems feasible. The key is to address practical issues, including information exchange about ACP and symptom management among all involved clinicians.

Introduction

Improved and novel cancer treatments enable patients with incurable cancer to live longer, giving rise to palliative care needs [1]. However, despite these medical advances, cancer remains a leading cause of death worldwide [2]. It has also been predicted that by 2040 cancer will be one of the main drivers of the increased need for palliative care [3]. The WHO defined palliative care as 'an approach that improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering through early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' [4].

A substantial body of literature has highlighted the importance of the timely integration of palliative care into oncology care for patients. It has been shown to improve patients' quality of life [5-9], reduce depressive symptoms [10, 11] and caregiver burden [12], increase satisfaction with care [13], decrease the chance of potentially inappropriate end-of-life care [14] and even prolong survival [5, 15]. These findings have led to in international guidelines, recommendations, criteria, and statements for early palliative care integration [16-19]. Thirteen major indicators of integrated palliative care and oncology for patients with incurable cancer were identified, such as an interdisciplinary hospital palliative care team, routine symptom screening in the oncology outpatient clinic, routine documentation of advance care plans, and early referral to specialist palliative care [20]. In the Dutch healthcare system, timely integration is sought through the application of the generalist-specialist model. In this model, all clinicians are considered palliative care generalists and provide palliative care as part of standard care, based on their basic medical skills. They are supported by palliative care specialists when needed. Palliative care specialists are (often) additionally trained in palliative care and organised in a specialist palliative care consultation team (SPCT). Clinicians can consult the SPCT for peer-to-peer consultation or refer patients to the team.

A recent Dutch Delphi study identified essential elements of the timely integration of palliative care for patients with incurable cancer were identified [21]. Based on these elements, three recommendations on advance care planning, routine symptom monitoring and the SPCT referral were formulated, including guidance on when, how and by whom these recommendations should be implemented. However, it is unclear whether applying these recommendations is feasible in everyday oncology practice. Therefore, we aimed to assess the feasibility of these recommendations by pilot testing them in the Dutch clinical context. Three research questions were addressed: (1) to what extent were clinicians able to apply the recommendations in daily clinical practice?, (2) to what extent are the recommendations applicable to clinicians?, and (3) how do patients assess the care they received?

Methods

Study design

The pilot study to assess the feasibility of the recommendations was conducted between November 2023 and March 2024. The applicability of the recommendations according to clinicians was assessed in month 4 (post-measurement) via a questionnaire that included the Measurement Instrument for Determinants of Innovations (MIDI) [22] and additional self-administrated questions. The electronic medical records (EMR) of patients with incurable cancer who were clinically admitted or seen as outpatients during month 3 of the pilot were assessed to analyse the extent to which clinicians could apply the recommendations (Figure 1). During the last month of the pilot period (month 3) patients received a questionnaire to assess their experiences with the received care using the EORTC IN-PATSAT32 and self-administrated questions.

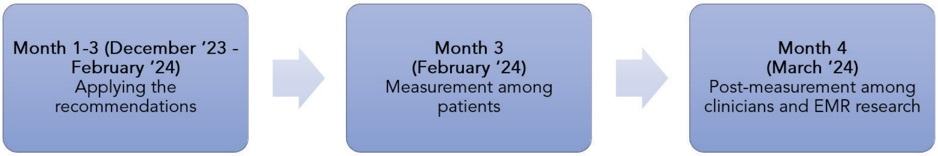

Figure 1 Research timeline by month

Setting

The four pilot hospitals were recruited using the expert panel from the previous Delphi study on elements of integrated care [21]. All clinicians involved were asked whether their department would want to participate. The four participating hospitals (one academic and three non-academic) included three medical oncology and one pulmonary oncology department. Two pilot hospitals implemented the intervention in both the in- and outpatient setting, one hospital in the outpatient and one in the inpatient setting.

Implementing the three recommendations

The pilot consisted of implementing the following three recommendations on timely integration of palliative care:

1. Offer advance care planning (ACP)[1] to all patient with incurable cancer and conduct a (follow-up) ACP discussion in the event of increased symptom burden, a life expectancy of <1 year (identified using the Surprise Question (SQ) ‘Would I be surprised if this patient dies within 12 months?’) and/or a change in line of treatment. Record the outcomes of these discussions in the EMR and share them with the primary care physician or involved institutional physician.

   [1] Advance care planning enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and clinicians, and to record and review these preferences if appropriate.[23]

2. Monitor symptoms and perform symptom management routinely across the four dimensions of Quality of Life (QoL) (physical, psychological, social and spiritual) in patients with incurable cancer with a life expectancy of <1 year. Record the outcomes of symptom monitoring and corresponding treatment decisions in the EMR.
3. Consider involving the SPCT in cases of complexity, such as symptom burden on multiple dimensions, and/or if the patient requests their involvement. Offer a consultation with the SPCT to patients with incurable cancer with life expectancy of <3 months (identified using the adapted Surprise Question (SQ) ‘Would I be surprised if this patient dies within 3 months?’).

To enable the pilot hospitals to use their existing workflows, the implementation of the three recommendations was tailored per hospital (Supplementary table 1).

Measures

The use of the recommendations

To assess the extent to which the recommendations were being applied, EMRs of all patients with incurable cancer who were admitted to the hospital and/or seen in the outpatient clinic during month 4 of the pilot were analysed by one or more assessors. These assessors were clinicians and assigned by the pilot hospital. The following information was extracted of the EMRs: patient characteristics (age, gender, tumour type), care setting (in- or outpatient), if the patient had already had an ACP discussion in the year previous to the study, and if so; whether the outcomes were shared with the general practitioner (GP) or involved institutional clinicians, whether the assessor, based on their own clinical knowledge, would be surprised if the patient died within 12 months, and if answered negatively, whether outcomes of symptom monitoring and corresponding treatment decisions were recorded, and whether the assessor would be surprised if the patient died within 3 months, and when answered negatively, if the patient was offered a consultation with the SPCT. The number of medical records to be analysed was set to a maximum of 150 patients per hospital.

Applicability of recommendations from clinicians' perspective

To evaluate the applicability of the recommendations according to clinicians who had implemented them, all clinicians received a questionnaire in month 4. This questionnaire included the MIDI instrument. The MIDI instrument has 29 items and uses a 5-point Likert scale response format ('strongly agree', 'agree', 'do not agree', 'do not disagree', 'disagree', 'strongly disagree') [22]. The only exception was the question on the number of colleagues that would adhere to the recommendations, which used a 7 point Likert-scale ('all colleagues', 'almost all colleagues', 'a majority', 'half', 'a minority', 'almost no colleague', 'not a single colleague'). The answer categories 'all colleagues', 'almost all colleagues' and 'a majority' have been recoded into 'agree' to comply with the answering format of the other items of the MIDI instrument. Additionally, 16 self- administrated questions were added to the questionnaire to assess clinicians' experience with the applicability of the recommendations (e.g. 'to what extent were you able to have discussions with patients with incurable cancer on lifegoals, choices and which care suits them now and in the future?'). The response format was a 5-point Likert scale ('very successful', 'successful', 'neutral', 'not successful', 'not successful at all').

Patients' experiences with the recommendations

To assess whether patients had received care in accordance with the recommendations, in month 3 participating clinicians asked all consecutive patients with incurable cancer who were admitted to the hospital or who visited the outpatient department to complete the questionnaire. Patients received an envelope containing the questionnaire, an information letter and an informed consent form that they could complete at home. Questionnaires could be returned using the included return envelopes. The questionnaire included 27 self-administrated questions (e.g. 'Did you discuss your goals, choices and what care suits them now and in the future with a clinician?').

Moreover, patients were also asked about their experiences with the received care; whether they experienced the care as pleasant and helpful and if they were content with the care they received. These questions were answered on a 5-point Likert-scale ranging from 'not at all' to 'very much'. This procedure was repeated in the last month of the pilot (month 4). Additionally the questionnaire included the European Organisation for Research and Treatment of Cancer In-patient Satisfaction with Care Questionnaire (EORTC IN-PATSAT32), which is a validated instrument measuring in-patient satisfaction with care [24]. Respondents assessed the skills of clinicians on a 5-point Likert scale (ranging from 'poor' to 'excellent'). Scores were linearly recoded to a 0-100 scale with higher scores indicating higher satisfaction.

Data analysis

Descriptive statistics were used to describe the sociodemographic characteristics, the MIDI and self-administrated questions of the clinicians' questionnaire, the EMR analysis, the experiences of patients, including their perceived satisfaction of care, continuity of care and continuity of information by patients. Based on previous research, aspects of the MIDI instrument were considered important for the applicability if ≥80 of the participants agreed or strongly agreed [25]. A priori, the minimum application of the intervention was set at 50%, meaning that at least 50% of the eligible patients should have received ACP, symptom burden assessment in all four dimensions and/or been offered SPCT consultation. If an ACP discussion had taken place, the outcomes should have been shared with the GP or involved institutional clinicians for at least 50% of these patients. Additionally, at least 50% of patients identified using the SQ 3 months should have been offered a consultation with the SPCT. A T-test for independent samples was used to compare satisfaction of care, continuity of care and continuity of information of patients who received care in accordance with the recommendations and those who did not. All analysis were conducted using Stata (version 17.0).

Ethical considerations

The study was assessed by the Medical Ethical Committee of Brabant (METC NW2023-44) and exempt from full approval of an ethics committee.

Results

The use of the recommendations

In total, 542 EMRs of patients with incurable cancer were analysed. Of these, 251 (46%) included male patients. The median age of the patients was 69 years (ranging from 24-96). The three most common tumour types were lung (23%), breast (20%) and prostate (13%). 508 (94%) were records of outpatients and 34 (6%) of inpatients. All aspects of the recommendations reached the threshold of 50%, except for conducting ACP discussions (49%) (Table 1). Among patients expected to be in their last year of life (n=220), the symptom burden on four dimensions and treatment decisions were recorded in 58% (n=127). More than half of patients with an expected life expectancy of ≤3 months (n=65) were offered a consultation with the SPCT (58%, n=38).

Table 1 Applying the recommendations in daily practice: EMR analysis of patients with incurable cancer (N=542)

	Yes n (%)
Advance Care Planning	
Was an ACP discussion conducted in the previous year?	267 (49)
If ACP was conducted: Were the outcomes of the ACP discussion shared with the GP and/or involved institutional physician?	224 (84)
Routine symptom monitoring	
A negative answer to the surprise question 12 months ('Would I be surprised if this patient died in the next 12 months?')	n=220
If SQ 12 months is negative: Were the outcomes of symptom monitoring on the four dimensions and corresponding treatment decisions recorded?	127 (58)
Involvement of SPCT	
A negative answer to the surprise question 3 months ('Would I be surprised if this patient died in the next 3 months?')	n=65
If SQ 3 negative: Were these patients offered a consultation with the SPCT?	38 (58)

Applicability of recommendations from clinicians' perspective

A total of 27 clinicians from three hospitals completed the questionnaire, ranging from 5-16 clinicians per hospital. One hospital did not return any questionnaires. Respondents were physicians (48%), nurses (48%), and one nurse practitioner (4%) with a mean age of 46 years (SD 10). Most were female (85%) and more than half (63%) had received additional training in palliative care (Supplementary table 2).

Most clinicians agreed with the statements that the three recommendations were important to achieve timely integration palliative care (84-85%) (Table 1).

Clinicians also agreed that: the recommendation fitted in with their tasks (88%), they had the required knowledge for implementing it (80%) and that it aided in achieving timely integration of palliative care (80%). Almost half of all clinicians thought that their colleagues would adhere to the recommendations of offering ACP (48%), start routine symptom monitoring (46%) and considering involving the SCPT in case of complexity and/or at patients' request and offering a consultation in case of a life expectancy of <3 months (56%).

Table 2 Applicability according to clinicians: results of the MIDI instrument

	Recommendation on advance care planning[1] (n=27)	**Recommendation on routine symptom monitoring[2] (n=26)**	**Recommendation on SPCT[3] (n=25)**
	Agree n (%)	**Agree n (%)**	**Agree n (%)**
It is important for achieving timely integration of palliative care for my patients	**23 (85)**	**21 (84)**[5]	**21 (84)**
It fits in with the tasks for which I feel responsible when doing my work	21 (78)	19 (73)	**22 (88)**
Colleagues are supportive when implementing it	20 (74)	20 (77)	16 (64)
I am aware of its content	19 (73)[5]	17 (68)[5]	19 (76)
Patients will be satisfied	19 (70)	17 (65)	18 (72)
Patients will cooperate	19 (70)	18 (69)	18 (72)
I have the required knowledge to implement it	19 (70)	18 (69)	**20 (80)**
It will probably aid in achieving timely integration of palliative care for my patients	17 (63)	13 (50)	**20 (80)**
I feel able to implement the activities involved with it	16 (59)	12 (48)[5]	19 (76)
It benefits me	15 (56)	10 (38)	16 (64)
Most colleagues will adhere to it[4]	13 (48)	12 (46)	14 (56)

Bold indicates a score above the threshold of 80%

[1] **Recommendation on ACP:** Offer advance care planning (ACP) to all patient with incurable cancer and conduct a (follow-up) ACP discussion in the event of increased symptom burden, a life expectancy of <1 year (identified using the Surprise Question (SQ) 'Would I be surprised if this patient dies within 12 months?') and/or a change in line of treatment. Record the outcomes of these discussions in the EMR and share them with the primary care physician or involved institutional physician.

[2] **Recommendation on routine symptom monitoring:** Routine symptom monitoring and symptom management across the four dimensions of Quality of Life (QoL) (physical, psychological, social and spiritual) in patients with cancer and a life expectancy of <1 year. Record the outcomes of symptom monitoring and corresponding treatment decisions in the EMR.

[3] **Recommendation on the SPCT**: Consider involving the SPCT in cases of complexity, such as symptom burden on multiple dimensions, and/or if the patient requests their involvement. Offer a consultation with the SPCT to patients with cancer and a life expectancy of <3 months (identified using the adapted Surprise Question 'Would I be surprised if this patient dies within 3 months?').

[4] Question had 7 answer options (1) not a single colleague, (2) almost no colleagues, (3) a minority, (4) half, (5) a majority, (6) almost all colleagues, (7) all colleagues)

[5] Missing n=1

Most clinicians reported that they were able to have ACP discussions (ranging from 63%-78%) (Table 3). Only 33% reported they were able to share the content with the GP or involved other institutional clinicians. Regarding symptom monitoring, 63% stated they were able to identify patients using the SQ, but only a minority monitored symptoms across the four dimensions (42%) and recorded the outcomes and corresponding treatment decisions in the EMR (19%). Most clinicians considered involving the SPCT in case of complexity and/or at patients' request and offered a consultation in case of a life expectancy of <3 months (ranging from 65%-85%).

Table 3 Applicability according to clinicians: additional self-questions (N=27)

Recommendation on Advance Care Planning

To what extent were you able to...	**Able n (%)**	**Neutral n (%)**	**Not able n (%)**
identify patients with incurable cancer[1]	25 (96)		1 (4)
have an ACP discussion (again) when there is a life expectancy of <1 year	21 (78)	5 (19)	1 (4)
record the content of ACP discussions in the EMR	18 (67)	7 (26)	2 (7)
have ACP discussions with patients with incurable cancer[1]	17 (65)	7 (27)	2 (8)
have this discussion (again) when there is a change in line of therapy	17 (63)	7 (26)	3 (11)
have this discussion (again) when there is an increased symptom burden?	17 (63)	6 (22)	4 (15)
integrate these discussions into your daily clinical work	16 (59)	7 (26)	4 (15)
share the content of these discussions with the GP or involved institutional physician?	9 (33)	10 (37)	8 (30)

Recommendation on routine symptom monitoring

To what extent were you able to...	**Able n (%)**	**Neutral n (%)**	**Not able n (%)**
identify patients with incurable cancer and a life expectancy of <1 year using the Surprise Question?	17 (63)	6 (22)	4 (15)
pay attention to symptom monitoring and symptom treatment on the four dimensions (physical, psychological, social and spiritual)?[1]	11 (42)	11 (42)	4 (15)
record outcomes of symptom monitoring on the four dimensions and corresponding treatment decisions in the electronic medical record?	5 (19)	12 (44)	10 (37)

Recommendation on SPCT

To what extent were you able to...	**Able n (%)**	**Neutral n (%)**	**Not able n (%)**
consider involving the SCPT at the patients' request?[1]	22 (85)	4 (15)	
consider involving the SPCT in case of complexity, such as symptom burden on multiple dimensions?[1]	19 (73)	7 (27)	
offer patients with an expected life expectancy of <3 months a consultation with the SPCT?[2]	17 (68)	8 (32)	
identify patients with incurable cancer and a life expectancy of <3 months using the Surprise Question?[1]	17 (65)	7 (27)	2 (8)

[1] Missing n=1
[2] Missing n=2

Patients' experiences with the recommendations

A total of 70 patients with incurable cancer completed the questionnaire (Table 4). The mean age was 63 years, and most patients had prostate cancer (19%) or breast cancer (16%).

Table 4 Social demographic characteristics of patients (N=70)

	n (%)
Gender	
Male	45 (64)
Female	25 (36)
Age (mean (SD); range min-max)	67 (12); 24-85
Marital status	
In a relationship, married and living together	52 (74)
In a relationship, not married and living together	6 (9)
In a relationship, not living together	2 (3)
Widow/widower/partner deceased	2 (3)
Single/no relationship	8 (12)
Educational level	
No education or primary education	2 (3)
Secondary (vocational) education	46 (66)
Bachelor's, master's or doctorate	20 (29)
m	2 (3)
Tumour type	
Colorectal	6 (9)
Breast	11 (16)
Prostate	13 (19)
Lung	8 (11)
Other[1]	25 (36)
m	7 (10)
Setting	
Outpatient	33 (47)
Inpatient	37 (53)

[1] Other tumours included melanoma, leukaemia, ovarium, brain, bladder, multiple myeloma, pancreas, gallbladder, bile duct, liver, lymph nodes and oesophagus)

In total, 62% of the patients reported to have had an ACP discussion. Whether symptoms had been monitored, according to patients, varied among the dimensions, ranging from 91% for the physical dimension to 38% for the spiritual dimension. More than half of the patients (53%) reported having had a consultation with a palliative care consultant (Table 5). Most patients found having an ACP discussion pleasant (70%) and helpful (74%). Regarding symptom monitoring, this varied per domain, with 70% finding it pleasant that the physician asked about physical symptoms and 46% regarding spiritual issues. When having a consultation with a member of the SPCT, 58% experienced it as pleasant and 42% as helpful. General satisfaction with care and continuity with care did not differ significantly between patients who did receive care according to the recommendations, except for symptom monitoring on the social dimension, respectively 83.1 (SD 18.7) vs 71.2 (SD 20.2), p=0.03 and 88.2 (SD 16.2) vs 77.5 (SD 22.3), p=0.03.

Table 5 Applicability according to patients, their experience of the received care and experienced satisfaction with care

Advance care planning	**Yes n (%)**	**No n (%)**	
Did you discuss your goals, choices and what care suits them now and in the future with a clinician?	43 (62)	26 (38)	
I found it pleasant	30 (70)		
I found it helpful	32 (74)		
I am content with it	32 (74)		
	Mean (SD)	**Mean (SD)**	**P-value**
General satisfaction with care	77 (21)	75 (21)	0.66
Continuity of care	82 (22)	81 (19)	0.79
Continuity of information	89 (20)	90 (23)	0.91
Routine symptom monitoring – physical dimension	**Yes n (%)**	**No n (%)**	
Did a clinician ask about your physical problems?	63 (91)	6 (9)	
I found it pleasant	44 (70)		
I found it helpful	42 (67)		
I am content with it	48 (76)		
	Mean (SD)	**Mean (SD)**	**P-value**
General satisfaction with care	77 (21)	71 (25)	0.50
Continuity of care	82 (21)	83 (18)	0.88
Continuity of information	90 (18)	78 (40)	0.16
Routine symptom monitoring – psychological/ emotional dimension	**Yes n (%)**	**No n (%)**	
Did a clinician ask about your psychological/emotional problems?	40 (57)	30 (43)	
I found it pleasant	25 (60)		
I found it helpful	23 (55)		
I am content with it	27 (64)		
	Mean (SD)	**Mean (SD)**	**P-value**
General satisfaction with care	79 (19)	73 (23)	0.28
Continuity of care	85 (21)	78 (20)	0.16
Continuity of information	93 (15)	84 (26)	0.08
Routine symptom monitoring – social dimension	**Yes n (%)**	**No n (%)**	
Did a clinician ask about your social problems?	31 (46)	37 (54)	
I found it pleasant	20 (65)		
I found it helpful	18 (58)		
I am content with it	21 (68)		
	Mean (SD)	**Mean (SD)**	**P-value**
General satisfaction with care	83 (19)	72 (20)	0.03*
Continuity of care	88 (16)	77 (22)	0.03*
Continuity of information	92 (17)	86 (24)	0.25
Routine symptom monitoring – spiritual dimension	**Yes n (%)**	**No n (%)**	

Table 5 Continued

Did a clinician ask about your spiritual challenges?	26 (38)	43 (62)	
I found it pleasant	12 (46)		
I found it helpful	13 (50)		
I am content with it	15 (58)		
	Mean (SD)	**Mean (SD)**	**P-value**
General satisfaction with care	80 (19)	74 (22)	0.30
Continuity of care	78 (25)	84 (18)	0.29
Continuity of information	90 (18)	89 (23)	0.91
Specialist Palliative Care Team – informed about consultation	**Yes n (%)**	**No n (%)**	
Were you informed about the possibility of having a consultation with a PC consultant?	32 (47)	36 (53)	
I found it pleasant	13 (39)		
I found it helpful	12 (36)		
I am content with it	18 (56)		
	Mean (SD)	**Mean (SD)**	**P-value**
General satisfaction with care	77 (20)	76 (22)	0.97
Continuity of care	81 (22)	81 (20)	0.96
Continuity of information	92 (17)	87 (24)	0.37
Specialist Palliative Care Team – having a consultation	**Yes n (%)**	**No n (%)**	
Did you have a consultation with a palliative care consultant?	19 (53)	17 (47)	
I found it pleasant	11 (58)		
I found it helpful	8 (42)		
I am content with it	10 (53)		
	Mean (SD)	**Mean (SD)**	**P-value**
General satisfaction with care	72 (20)	81 (24)	0.26
Continuity of care	79 (17)	90 (20)	0.07
Continuity of information	88 (19.9)	92 (25)	0.56

Discussion

Main findings

This pilot study has assessed the clinical feasibility of implementing three recommendations on timely integration of palliative care into oncology. Clinicians were able to apply the recommendations in approximately half to two-thirds of their patients with incurable cancer. Moreover, clinicians rated all three recommendations as important, but some practical implications of the recommendations require further attention. Most patients for whom the recommendations were applied found this helpful and were satisfied with their care. Overall satisfaction with their care and continuity of care did not differ significantly between patients who received care according to the recommendations and those who did not, with the exception of symptom monitoring of the social dimension.

Advance care planning

In the present study, clinicians were willing to integrate ACP discussions for patients with incurable cancer into their daily practice, however applying the ACP recommendation in clinical practice proved challenging. The recommendation on ACP scored just below the 50% threshold and a significant number of clinicians reported being ‘neutral’ or ‘not able’ to integrate ACP into their daily clinical practice. While this pilot study did not collect data on barriers experienced, there is a substantial body of literature on barriers for the integration of ACP. Barriers include knowledge (e.g. having insufficient understanding of ACP), environmental context and resources (e.g. time constraints), emotions (e.g. fear of diminishing patients’ hope) and skills (e.g. lack of training) [26]. To support clinicians and increase their knowledge and skills about ACP, a variety of tools are available to introduce and facilitate ACP discussions [27], both patient-facing tools [28] and interactive web-based ACP support tools [29].

While time is a well-known barrier, a recent randomised clinical trial demonstrated the durability of long-term ACP, with a reduction in the use of acute, complex or invasive care and an increase in palliative- and hospice care in a timely manner in patients’ disease trajectory [30]. This highlights the fact that the time investment required to integrate ACP will ultimately result in important benefits for clinicians, patients and the wider healthcare system.

Only 33% of clinicians shared the outcome of ACP discussions with the GP or other involved institutional clinicians, yet this coordination and collaboration with primary care providers is essential for proper integration of ACP. This finding is consistent with another national study that also showed suboptimal sharing of important information between oncologists and GPs [31]. A standardised format and documentation that is accessible across care settings is needed to improve this exchange and thus continuity of care. Preferably an automated report derived from the EMR that can be sent to all clinicians involved after an ACP discussion is conducted. Having a method of documentation that is accessible to different clinicians allows the ACP discussions to be conducted by different clinicians at different points in the disease trajectory, such as the treating physician, trained case managers, oncology nurses, or the GP. This reinforces the idea that ACP should be seen as an ongoing standard of care within the network of involved clinicians, rather than an optional consultation.

Routine symptom monitoring

Integrating routine symptom monitoring into cancer care has been shown to improve health-related quality of life [32, 33]. Additionally, self-reported information can facilitate and improve the communication and discussion between clinicians and patients [34, 35]. Accordingly, the clinicians participating in the current study reported that they considered routine symptom monitoring to be important. However, clinicians were ambiguous regarding their ability to monitor symptom burden across the four dimensions and record the outcomes in the EMR. There are different ways in which clinicians monitor symptoms, including eliciting symptoms during clinical visits, often without a structured discussion format, to using a symptom diary that patients complete in a structural way. Proper integration of these methods requires a dedicated place in the EMR. And while a variety of digital methods and tools for monitoring symptoms with electronic patient-reported outcomes have been developed [36-39], many hospitals are still developing fitting (digital) infrastructure and standard operation of procedure into their clinical workflow.

Furthermore, less than half of the clinicians believed that their colleagues would adhere to the recommendation. This assumption may be due to known barriers to implementing symptom monitoring, such as concerns about additional workload, scepticism about the benefits for oncological treatment and usability issues [40, 41]. To use patient-reported outcomes, the system used must be applicable to all patients, easily adaptable, and compatible with the existing workflows [41, 42]. This finding may also be prompted by the fact that most clinicians who completed the post-assessment were additionally trained in palliative care and may therefore have had less positive experiences and perceptions of their generalist palliative care colleagues' motivation and ability to integrate palliative care in a timely manner.

Patients experienced symptom monitoring on the psychological, social and spiritual dimensions less comfortable and helpful than symptom monitoring on the physical dimension. This may also be related to the tendency of healthcare providers to focus only on the physical dimension (e.g., dyspnoea or pain) rather than adequately addressing psychological or social issues. Another possible explanation for patients' reluctance to discuss psychosocial issues might be the stigma associated with psychosocial needs [43-46]. Additionally, a systematic review showed that patients vary widely in their appreciation of being asked about spirituality. Most of the included studies reported that patients found it appropriate for their physicians to ask about religion or spirituality. However, when dealing with spiritual issues, patients do not expect or want spiritual guidance from their physicians, but would rather talk to clergy [47].

Specialist Palliative Care Team

Most SPCTs in the Dutch hospitals have limited occupancy and therefore limited capacity. It is therefore not feasible to refer all patients with palliative care needs to the SPCT. It has therefore been suggested that the only sustainable model is a generalist-specialist model in which all clinicians provide basic or primary palliative care with the SPCT assisting with complex cases [48, 49]. However, it is known that the SPCT is often involved (too) late in the disease trajectory of patients with incurable cancer [50, 51].

This recommendation follows the results of a previous Delphi study in which clinicians, patients and relatives reached a consensus on the minimal thresholds for involving the SPCT in a generalist-specialist model [21]. However, if the SPCT is to be involved in cases of complexity, further research is needed to define complexity and identify ways of integrating the classification system into clinical practice [52]. In addition, timeliness may not be ensured if SPCT involvement is considered only for symptom burden on more than one dimension, as symptom burden increases significantly in the last phase of life, with the greatest increase in the last three months [53]. Appropriate symptom management at the end of life can be provided by palliative care generalists if they are skilled enough to provide high quality generalist palliative care. Elements of high-quality generalist palliative care include: general and psychosocial symptom assessment and management, providing patients with basic spiritual support, such as a framework to consider their goals and hopes and timely referral to a spiritual counsellor if needed; and starting the process of advance care planning (ACP) soon after the initial diagnosis of advanced cancer [54]. At present, however, palliative care training is not integrated into medical education and clinicians are not required to undertake additional training, although steps are being taken to improve the curriculum [55].

Not all patients in our pilot found it particularly helpful to be informed about the possibility to come into contact with palliative care consultants of the SPCT. This may be related to the misconceptions about palliative care, for example that it is the same as terminal care or hospice care, or that it means stopping all other treatments [56, 57].

Strengths and limitations

This study demonstrates the feasibility of three recommendations on timely integration of palliative care into standard hospital oncology care. Our study has several strengths and limitations. A strength was that it followed the results of a Delphi study and the recommendations were therefore in line with current clinical practice and ambitions. Additionally, a mixed method approach was used to provide complimentary insights into the feasibility of the recommendations. Some limitations should also be noted. First, the clinicians using the recommendations in the pilot hospitals may have been more aware of the benefits of integrating palliative care into oncology practice. Therefore, both clinician and patient outcomes may have been more positive than in other hospitals. Second, when analysing the EMRs, the presence of an indication that an ACP discussion took place does not provide a detailed insight into the actual content or depth of the discussion. This also holds for the indication of an exchange of information with primary care physicians in the EMR, which does not indicate the method of exchange (via a telephone call or via a standard information letter). In addition, there may have been patients who had had ACP discussions before the start of the pilot and for whom there was no indication to have another ACP discussion during the pilot. Therefore, in the EMR analysis, we looked at whether patients had had an ACP discussion in the year prior to the pilot study, and if so, this would suggest that the recommendation was already being applied and therefore applicable. However, the study did not collect data on when the ACP discussions took place. In addition, the EMR analysis was not always performed by the treating physician, and the investigator was asked to answer the surprise questions of one year and three months based on his or her own clinical judgement. Finally, patient assessment was mainly descriptive. The pilot was of short duration, which made it impossible to measure real effects over time.

Conclusion

Implementing the three recommendations regarding ACP, routine symptom monitoring, and involvement of the Specialist Palliative Care Team (SPCT) in daily oncological care for patients with advanced cancer seems feasible, as clinicians were able to apply the recommendations in almost half of the patients and found them to be important. To truly improve care with the use of these recommendations some practical issues need to be addressed regarding continuity of care, including information exchange about ACP and symptom management amongst all involved clinicians within the hospital and with primary care clinicians.

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Supplementary table 1 Implementation of recommendations per hospital

	Hospital 1	**Hospital 2**	**Hospital 3**	**Hospital 4**
Setting	In- and outpatient of oncology department	In- and outpatients of oncology department	Outpatients of oncology department	In- and outpatients department of lung oncology
ACP discussions for all patients with incurable cancer				
- How were patients informed about ACP discussion(s)?	Verbally	Verbally	Verbally and through leaflet	Verbally
- Who conducted the ACP discussion(s)?	Oncologist or nurse practitioner	A consultant of the SPCT	Case manager and/or consultant of the SPCT	A consultant of the SPCT
- How were the ACP discussion(s) recorded?	EMR	Existing format in EMR		Existing format in EMR
- How were the outcomes of exchanged with the primary care physician or involved institutional physician?	By phone or letter	By letter	By letter	By letter
Symptom monitoring for all patients with a life expectancy of < 1 year				
- Who identified patients with a life expectancy of < 1 year	Oncologist	Oncology nurses	Oncologist	Case manager in coordination with treating physician
- Which tool was used to monitor symptoms?	USD-4	USD-4	USD-4	Existing format in EMR which includes the Hospital Anxiety and Depression Scale and Distress Thermometer
- How often were symptoms monitored?	During every visit	During every visit, at least every 3 months	4 times a year	At least once a month, with a maximum of once a week

Supplementary table 1 Continued

	Hospital 1	Hospital 2	Hospital 3	Hospital 4
Consider to involve the SPCT in cases of complexity, such as symptom burden on multiple dimensions, and/or if the patient requests their involvement				
- How were patients identified?	Symptom burden on more than 1 dimension on the USD-4	Symptom burden on more than 1 dimension on the USD-4	Using the USD-4 and clinical assessment of patients functioning, problems on the psychological or existential domain	Using an existing app and clinical assessment
- Who identified patients?	Oncologist	Nurses		Treating physician and case manager
Offering patients a consultation with a consultant of the SPCT for all patients with a life expectancy of <3 months				
- How were patients identified?	Clinical assessment		Clinical assessment and problems on psychological and existential domain	Clinical assessment
- How were patients informed about the SPCT?	Verbally		Verbally and through a leaflet	Verbally and through a leaflet
- Who offered patients a consultation with a consultant of the SPCT?	Oncologist or nurse practitioner	Nurses	Case manager in coordination with treating physician	Case manager in coordination with treating physician

Supplementary table 2 Sociodemographic characteristics of clinicians (N=27)

	n (%)
Age (mean (SD); range min-max)	46 (10); 33-66
Sex	
Female	23 (85)
Male	4 (15)
Profession	
Physician	13 (48)
Nurse practitioner	1 (4)
Nurse	13 (48)
Additionally trained in palliative care	
No	10 (37)
2-years palliative care CME[1] for physicians	2 (7)
9-day course in palliative care for physicians	3 (11)
Nurses with 1-year palliative care CNE[2]	3 (11)
Courses on palliative care	8 (30)
Internship palliative care within the hospital	1 (4)

[1] CME: Continuing medical education
[2] CNE: Continuing nursing education

Supplementary table 3 Applying the recommendations in daily practice per hospital

	Hospital 1 (N=150)	Hospital 2 (N=125)	Hospital 3 (N=150)	Hospital 4 (N=117)	Total (N=542)
	Yes n (%)	**Yes n (%)**	**Yes n (%)**	**Yes n (%)**	**Yes n (%)**
Advance Care Planning					
Was an ACP discussion conducted in the previous year?	96 (64)	56 (45)	72 (48)	43 (37)	267 (49)
If ACP was conducted: Were the outcomes of the ACP discussion shared with the GP and/or involved institutional physician?	96 (100)	34 (61)	70 (97)	24 (56)	224 (84)
Routine symptom monitoring					
A negative answer to the surprise question 12 months ('Would I be surprised if this patient died in the next 12 months?')	n=79	n=61	n=36	n=44	n=220
If SQ 12 months is negative: Were the patients' functioning on the four dimensions and/or the treatment agreements recorded in the EMR?	58 (73)	30 (49)	20 (56)	19 (43)	127 (58)
Involvement of SPCT					
A negative answer to the surprise question 3 months ('Would I be surprised if this patient died in the next 3 months?')	n=18	n=14	n=10	n=23	n=65
If SQ 3 negative: Were these patients offered a consultation with the SPCT?	13 (72)	7 (50)	8 (80)	10 (83)	38 (58)

CHAPTER 6

Provision of key components of palliative care in everyday practice in Dutch hospitals

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Abstract

Objective To examine the provision of key components of palliative care (PC) in Dutch hospitals, and to identify associated hospital- and specialist palliative care team (SPCT) characteristics.

Data sources and study setting SPCTs from all 72 Dutch hospitals were invited to an online survey about PC practices in their hospital.

Study design Data from a cross-sectional national survey among Dutch hospital-SPCTs was used. The survey, conducted from January to March 2024, included questions about hospital- and SPCT characteristics, and the current provision of key components of PC in hospitals, namely advance care planning (ACP) and routine symptom monitoring. Hospitals with and without implemented ACP and routine symptom monitoring were compared.

Principal findings In total 58 hospitals participated (81%), with a median annual admission of 20,456 inpatients (IQR 12,787) and a median SPCT referral rate of 1.4% (IQR 1.4%) of annual admissions. Routine ACP discussions were held in 58% of hospitals, with 12% consistently implementing ACP across the hospital. No differences in hospital- and SPCT characteristics were found between hospitals with or without routine ACP discussions. In 59% of hospitals, symptoms of outpatients were screened using a tool. These hospitals had both a higher SPCT referral rate (median of 330 (IQR 119) vs. 175 (IQR 279), $p<0.05$) and more inpatient SPCT referrals compared to those without monitoring (1.7% vs. 1.1%, $p<0.05$). Moreover, hospitals with routine symptom monitoring were more likely to offer an internship with SPCTs (70% vs 35%) and PC education (61% vs 17%) compared to those without ($p<0.05$).

Conclusions Routine ACP discussions and symptom monitoring in outpatients do not yet seem common practice in Dutch hospitals. SPCTs can play an important role to further implement these key elements, together with guidelines, educational programs and a digital infrastructure for reporting and sharing outcomes.

Introduction

As the global population continues to age and the prevalence of chronic illness increases, the need for palliative care (PC) rises [1]. PC offers significant benefits for patients, including improved quality of life, reduced depressive feelings and symptom burden, and increased satisfaction with care [2-8]. Additionally, PC benefits relatives by reducing stress and depression, and enhancing their satisfaction with care [9, 10].

To realise these benefits for patients and their relatives, various medical organisations have issued guidelines and recommendations on the integration of PC into standard care, including for patients with cancer or chronic obstructive pulmonary disease [11, 12]. The Lancet Oncology Commission has highlighted several models to facilitate this integration, including the role of hospital-based specialist palliative care teams (SPCTs) as a key component [13]. The Dutch healthcare system aims to integrate PC through a generalist-specialist model. In this model, all clinicians are expected to provide generalist PC based on their medical training, including advance care planning, basic symptom management, and supportive and end-of-life care in line with the patient's preferences [14]. PC specialists have additional expertise and broad experience in PC and can support PC generalists when needed, e.g. in case of complex symptom burden. Over the years, hospital-wide integration of the SPCTs in Dutch hospitals have progressed significantly [15]. A previous study identified characteristics related to high involvement of SPCTs, such dedicated outpatient clinics and the provision of education [16]. A national Dutch Delphi study on oncology hospital care identified structural implementation of advance care planning (ACP), routine symptom monitoring and the involvement of the SPCTs as key components of timely integration of PC into standard care in a generalist-specialist model [17].

For an effective and timely integration of PC into hospital care, it is essential to better understand the current provision of these key components, and how they are associated with hospital- and SPCT-characteristics. However, little is known about the current provision of ACP and routine symptom monitoring and which hospital- and SPCT characteristics are related to these practices. Therefore, the aim of this study was to examine the current provision of key components of PC in everyday practice of Dutch hospitals, and to identify associated hospital- and SPCT characteristics.

Methods

Study design

Data from a national cross-sectional survey was used for analysis. The survey was conducted from January to March 2024 as part of a three yearly assessment of PC in Dutch hospitals. The results of the primary analysis have been reported elsewhere [18]. To ensure the quality of reporting, the STROBE reporting guidelines for cross-sectional studies were adhered to [19].

Setting and participants

Key members of the SPCTs from all 72 hospitals in the Netherlands were invited to participate in an online survey. These hospitals included general, teaching and academic hospitals, as well as dedicated cancer centres.

Questionnaire

The questionnaire was developed as part of a three-yearly survey. The 2015 questionnaire was pilot tested for face validity, reliability, and questionnaire length by members of a SPCT [20]. Each subsequent questionnaire was reviewed and updated to reflect relevant developments in the SPCTs at the time of the survey. The questionnaire included questions about hospital- and SPCT characteristics, as well as the current provision of key components of PC in hospitals. The 2024 survey, used for this study, was administered online using Survey Monkey, with email and telephone reminders sent to non-responders. Incomplete responses were followed up by email to encourage completion.

Hospital- and SPCT characteristics

The first part of the questionnaire included items on hospital characteristics, such as hospital type, number of hospital admissions and SPCT referral rate. It also included questions about SPCT characteristics, such as number of annual inpatient SPCT referrals and the possibility for an internship with the SPCT.

Current provision of key components of PC in hospitals

The current provision of PC in hospitals was assessed based on two key components: advance care planning (ACP) and routine symptom monitoring [17]. ACP was evaluated by asking whether routine ACP discussions were conducted within the hospital (“Are advance care planning discussions conducted routinely within the hospital?”). Routine symptom monitoring was assessed by asking whether symptoms in outpatients were routinely screened using a tool (“Are symptoms routinely screened in outpatient patients using a tool?”).

Hospital- and SPCT characteristics by key components of PC in hospitals

To assess which hospital- and SPCT characteristics are related to the current provision of key components of PC, we assessed whether these characteristics differed between hospitals with and without routine ACP discussions and between hospitals with and without routine symptom monitoring in outpatients.

Statistical analysis

Descriptive statistics were used to summarise the hospital- and SPCT characteristics and the key components of PC. Data were presented as numbers and percentages for categorical variables and as median and interquartile range (IQR) for non-normally distributed continuous variables. Missing data on the number of hospital admissions per year were supplemented by annual reports of the hospitals. Missing data were reported for variables with more than 5% missing values. The SPCT referral rate was calculated as the number of annual inpatient referrals to the SPCT as a percentage of the number of total annual hospital admissions. Hospital- and SPCT characteristics were compared by key components of PC in univariate analyses using Chi-square tests for categorical variables and Kruskal-Wallis tests for non-normally distributed continuous variables. P-values < 0.05 were considered statistically significant. Statistical analyses were performed using STATA version 17 (StataCorp LLC, Texas, USA).

Results

All 72 hospitals in the Netherlands were invited and 58 hospitals participated in the survey, yielding a response rate of 81%.

Hospital- and SPCT characteristics

The participating hospitals had a median annual admission of 20,456 inpatients (IQR 11,889-24,676) and a median SPCT referral rate of 1.4% (IQR 0.8-2.2%). Most hospitals were general (43%) or teaching (40%) hospitals. The median number of annual inpatient SPCT referrals was 276. More than half of the hospitals had a dedicated PC outpatient clinic (53%) (Table 1).

Table 1 Hospital- and SPCT characteristics

	Total (N=58)
Number of hospital admissions / year (median, IQR)	20,456 (12,787)
SPCT referral rate [1] (median, IQR)	1.4 (1.4)
No of yearly inpatient SPCT referrals (median, IQR)	276 (261)
	n (%)
Type of hospital	
General	25 (43)
Teaching	23 (40)
Academic	8 (14)
Specialised	2 (3)
PC assignment of the hospital executive board	34 (61)
Presence of SPCT	58 (100)
Presence of dedicated PC outpatient clinic	30 (53)
Participation of SPCT in MDTMs [2] of other departments	30 (53)
Presence of didactic PC curriculum [3]	58 (100)
Combined PC and oncology educational activities [4]	30 (55) [5]
Possibility for internship with SPCT [6]	31 (55)
Continuing medical education in PC for attending oncologists	24 (43)
Organisation of symposia by SPCT	42 (72)

[1] Palliative care referral rate calculated as the number of annual inpatient referrals to the specialist palliative care team as a percentage of the number of total annual hospital admissions
[2] MDTM Multidisciplinary team meeting
[3] Education provided to nurses, interns, residents and / or fellows hospital-wide
[4] Educational activities for fellows/trainees and nurses
[5] N=55 (3 missings)
[6] Possibility for residents and / or fellows hospital-wide or general practitioner trainees

Current provision of key components of PC in hospitals

Routine ACP discussions were held in 58% of hospitals, with only 12% implementing it consistently across the hospital, 39% limiting it to specific departments, and 7% focusing on specific diagnoses. In 59% of hospitals, symptoms in outpatients were routinely screened using a tool. While physical and psychological dimensions of quality of life were almost always included in the used measurement tools (100% and 95%, respectively), the social and spiritual dimensions were addressed in only 57% (Table 2).

Hospital- and SPCT characteristics by key components of PC in hospitals

Hospitals with routine symptom monitoring in outpatients had a higher median SPCT referral rate (1.7%) and more annual inpatient referrals (330) compared to those without monitoring (1.1% and 175, respectively; $p<0.05$). Additionally, hospitals with routine symptom monitoring were more likely to offer internships with SPCTs (70%) and continuing medical education in PC for attending oncologists (61%) compared to those without routine symptom monitoring (35% and 17%, respectively; $p<0.05$) (Table 3). No significant differences in hospital- and SPCT characteristics were observed between hospitals with or without routine ACP discussions.

Table 2 Current provision of key components of PC in 58 Dutch hospitals

	Total (N=58)
	n (%)
Use of instruments within hospital to identify patients with potential PC needs	50 (86)
Medical specialties routinely screening outpatients for potential PC needs	
Oncology	36 (62)
Respiratory medicine	20 (34)
Geriatrics	18 (31)
Cardiology	10 (17)
Internal medicine	8 (14)
Neurology	6 (10)
Advance care planning (ACP)	
Routine ACP discussions within hospital	
Yes	7 (12)
Yes, but only for specific departments [1]	22 (39)
Yes, but only for specific diagnoses [2]	4 (7)
No	24 (42)
ACP included as a standard component of care in the care policy	21 (36)
Use of digital ACP form within hospital	20 (35)
Fixed moments in the disease trajectory for ACP discussions	10 (18)
Involvement of SPCT in ACP discussions	15 (26)
ACP included in education for generalist clinicians provided by the SPCT	37 (67) [3]
ACP standard topic in MDTM [4] of the SPCT	37 (66)
Routine symptom monitoring	
Routine symptom monitoring in outpatients using a tool	34 (59)
Use of measurement tools by the SPCT	44 (76)
Dimensions of quality of life included in the used measurement tool	
Physical	44 (100)
Psychological	42 (95)
Social	25 (57)
Spiritual	25 (57)

[1] Primarily for departments oncology, pulmonology, and cardiology
[2] Primarily for diagnoses COPD and heart failure
[3] N=55 (3 missings)
[4] MDTM Multidisciplinary team meeting

Table 3 Hospital- and SPCT characteristics by key components of PC

	Routine ACP discussions [1] (n=33)	**No routine ACP discussions (n=24)**	**Routine symptom monitoring [2] (n=34)**	**No routine symptom monitoring (n=24)**
Number of hospital admissions / year (median, IQR)	20,596 (12,053)	19,128 (12,625)	21,559 (8,768)	16,901 (13,191)
SPCT referral rate [3] (median, IQR)	1.3 (1.0)	1.5 (1.5)	**1.7 (1.4)***	**1.1 (1.3)***
No of yearly inpatient SPCT referrals (median, IQR)	311 (287)	249 (213)	**330 (199)***	**175 (279)***
	n (%)	**n (%)**	**n (%)**	**n (%)**
Type of hospital				
General	14 (42)	10 (42)	12 (35)	13 (54)
Teaching	13 (39)	10 (42)	13 (38)	10 (42)
Academic	5 (15)	3 (13)	7 (21)	1 (4)
Specialised	1 (3)	1 (4)	2 (6)	0 (0)
PC assignment of the hospital executive board	19 (61)	14 (58)	22 (69) [4]	12 (50)
Presence of dedicated PC outpatient clinic	17 (52)	13 (57)	21 (64)	9 (38)
Participation of SPCT in MDTMs [5] of other departments	15 (45)	15 (63)	19 (58)	11 (46)
Combined PC and oncology educational activities [6]	17 (55)	13 (54)	19 (59) [4]	11 (48)
Possibility for internship with SPCT [7]	17 (53)	14 (58)	**23 (70)***	**8 (35)***
Continuing medical education in PC for attending oncologists	15 (47)	9 (38)	**20 (61)***	**4 (17)***
Organisation of symposia by SPCT	24 (73)	18 (57)	27 (79)	15 (63)

* p-value < 0.05

[1] Advance care planning included as routine ACP discussions within the entire hospital, for certain departments, or for certain diagnoses

[2] Routine symptom monitoring included as routine symptom monitoring in outpatients using a tool

[3] Specialist palliative care team referral rate calculated as the number of annual inpatient referrals to the SPCT as a percentage of the number of total annual hospital admissions

[4] N=32 (2 missings)

[5] MDTM Multidisciplinary team meeting

[6] Educational activities for fellows/trainees and nurses

[7] Possibility for residents and / or fellows hospital-wide or general practitioner trainees

Discussion

Summary

This study examined the current provision of advance care planning (ACP) and routine symptom monitoring as key components of palliative care (PC, in Dutch hospitals. In 2023, routine symptom monitoring in outpatients and routine ACP discussions were partly implemented in hospitals. Routine symptom monitoring in outpatients was associated with a higher SPCT referral rate, offering an internship with the specialist palliative care team, and a higher likelihood to provide palliative care education for generalists. However, no significant differences in hospital- and SPCT characteristics were found between hospitals with or without routine ACP discussions.

Advance care planning

Our findings indicate that while many hospitals are progressing toward implementing routine ACP discussions, the implementation across the entire hospital remains limited. The importance of ACP is widely acknowledged, for example by Dutch clinicians in a recent study [17], and reinforced by the National Palliative Care Program II, which identifies ACP as a core theme for the integration of PC into standard care [21]. In addition, to enhance clinicians' ability to conduct ACP discussions, the Dutch Healthcare Authority has established a dedicated payment code for Dutch hospitals, enabling clinicians to bill for ACP discussions from January 2025. ACP is associated with several benefits, such as increased use of hospice and PC services, better alignment between care preferences and the care provided, and adherence to patients' end-of-life wishes, as well as less life-sustaining treatment and fewer hospital admissions [22, 23]. The limited adoption of routine ACP discussions may reflect underlying systemic barriers. Known barriers to the implementation of ACP discussions include the absence of a standardised location for ACP documentation in the electronic health record [24]. Our data show that only 35% of hospitals use a digital ACP form. Another known barrier is the lack of integration of ACP into existing clinical workflows [25]. We found that only 18% of hospitals report having fixed moments in the disease trajectory for ACP discussions. Insufficient time is an additional known barrier [26]. Additionally, concerns that ACP discussions may result in depression or feelings of hopelessness in patients may hinder their adoption [27]. However, perceptions of involvement in ACP have been found to be positively associated with emotional functioning in patients [28].

No significant differences in hospital- and SPCT characteristics were found between hospitals with or without routine ACP discussions implemented in the workflows for specific diagnoses or departments caring for patients with life limiting diseases. We expected an association, as SPCTs may contribute to the integration of PC across the hospital by supporting and training generalists as well as developing care pathways [29]. As such, a stronger association between routine ACP discussions and SPCT characteristics was expected, but the extent to which ACP is implemented across hospitals may have diluted the overall effect. Including only the hospitals with routine ACP discussions across the entire hospital (n=7, 12%) had insufficient significant power, but suggested possible associations (Supplementary Table 1).

Routine symptom monitoring

Our findings show that in 59% of hospitals, symptoms in outpatients were routinely screened using a tool. This practice is important, as higher symptom burden can negatively impact patients' quality of life [30, 31]. To increase the practice of routine symptom monitoring it is essential to address barriers to its integration. Known barriers are tools that are burdensome for patients, their relatives and health care providers, lack of training for the use of tools as well as financial constraints [32]. Additionally, effective symptom monitoring should address all four dimensions of PC - physical, psychological, social, and spiritual - as failing to do so may miss important aspects of patients' well-being. However, our findings indicate that while physical and psychological dimensions were nearly always included in measurement tools (100% and 95%, respectively), social and spiritual dimensions were addressed in only 57% of the measurement tools used by hospitals.

Hospitals where symptoms in outpatients were routinely screened using a tool, demonstrated a SPCT that was more involved in clinical and educational activities. These hospitals had a higher median SPCT referral rate and more yearly inpatient SPCT referrals, and were more likely to offer internships with SPCTs and continuing medical education in PC for attending oncologists compared to those without routine symptom monitoring. While these practices appear to reinforce one another, the direction of influence remains uncertain due to the cross-sectional nature of our study, leading to potential reverse causality. This means that the practice of routine symptom monitoring may lead to higher SPCT referral rates since complex symptom burden is identified more often, while at the same time SPCT involvement could enhance symptom monitoring through education and training initiatives [33]. Additionally, it should be noted that the higher level of educational activities in hospitals with routine symptom monitoring, could also be attributed to the fact that this group consists of more academic hospitals (21%) compared to hospitals without routine symptom monitoring (4%).

Strengths and limitations

This is a national study to examine the current provision of key components of palliative care (PC) in Dutch hospitals and therefore provides valuable information. The survey achieved a high response rate, suggesting that our findings are likely to be generalizable to all Dutch hospitals. However, several limitations should be considered. First, the data were self-reported by members of the hospital SPCTs, which may have introduced information bias due to gaps in knowledge, as SPCT might not have been fully aware of PC practices within all departments across the hospital. Additionally, reporting bias could have occurred if respondents provided socially desirable answers to present their hospital more favourably. To minimise this potential bias, we assured participating hospitals that their responses would remain anonymous. Furthermore, while our study provides insight into the extent to which ACP and routine symptom monitoring in outpatients has been implemented in hospitals, the questionnaire did not capture information on the quality of these practices, such as the content of ACP discussions, their perceived value for patients, the documentation by clinicians, or whether there was follow-up after routine symptom monitoring [28, 34-36].

Practical implications

The current provision of key components of PC in hospitals suggests there is potential for improvement, as not all hospitals have fully implemented ACP and routine symptom monitoring. To address this, efforts should focus on increasing awareness of PC and providing education on conducting ACP discussions, particularly among generalist PC providers. SPCTs can play a central role in advocating for the value of PC and training generalist PC providers. Facilitating this collaboration between generalist PC providers and the SPCT can foster the integration of PC across the hospital, ensuring that PC becomes an integral part of standard care. Efforts should simultaneously be directed toward improving clinical processes of PC, such as establishing clear protocols for referral pathways and standardised locations for documentation of ACP [13].

Conclusion

While many Dutch hospitals have integrated routine advance care planning (ACP) discussions and symptom monitoring in outpatient clinics, there remains significant room for improvement. Hospitals that systematically screen outpatients for symptoms using standardised tools tend to have more engaged SPCTs in both clinical and educational activities. However, the direction of this influence remains uncertain. SPCTs can play a key role in further embedding these practices by leading educational initiatives. Overcoming common barriers—such as time constraints, insufficient digital infrastructure for reporting and sharing outcomes, and the need for clear guidelines and training programs for generalist providers—will be crucial for successful implementation. Additionally, strategic investments in SPCTs will help ensure that palliative care is consistently delivered throughout hospitals, fostering collaboration between generalist and specialist providers and ensuring that patients and their families receive timely, high-quality care. Further research is needed to evaluate the integration of ACP and symptom monitoring in daily clinical practice and to identify effective strategies for optimizing their implementation.

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Supplementary table 1 Hospital- and SPCT characteristics by key components of PC in hospitals

	Routine ACP discussions [1] (n=7)	**No routine ACP discussions (n=50)**	**Routine symptom monitoring [2] (n=34)**	**No routine symptom monitoring (n=24)**
Number of hospital admissions / year (median, IQR)	20,596 (14,379)	20,626 (11,932)	21,559 (8,768)	16,901 (13,191)
SPCT referral rate [3] (median, IQR)	1.3 (2.8)	1.4 (1.2)	**1.7 (1.4)***	**1.1 (1.3)***
No of yearly inpatient SPCT referrals (median, IQR)	263 (255)	291 (261)	**330 (199)***	**175 (279)***
	n (%)	**n (%)**	**n (%)**	**n (%)**
Type of hospital				
General	2 (29)	22 (44)	12 (35)	13 (54)
Teaching	3 (43)	20 (40)	13 (38)	10 (42)
Academic	1 (14)	7 (14)	7 (21)	1 (4)
Specialised	1 (14)	1 (2)	2 (6)	0 (0)
PC assignment of the hospital executive board	3 (43)	30 (63)	22 (69) [4]	12 (50)
Presence of dedicated PC outpatient clinic	5 (71)	25 (51)	21 (64)	9 (38)
Participation in MDTMs [5] of other departments	4 (57)	26 (52)	19 (58)	11 (46)
Combined PC and oncology educational activities [6]	5 (83)	25 (51)	19 (59) [4]	11 (48)
Possibility for internship with SPCT [7]	5 (83)	26 (52)	**23 (70)***	**8 (35)***
Continuing medical education in PC for attending oncologists	4 (67)	20 (40)	**20 (61)***	**4 (17)***
Organisation of symposia by SPCT	5 (71)	37 (74)	27 (79)	15 (63)

* p-value < 0.05

[1] Advance care planning included as routine ACP discussions within the entire hospital, for certain departments, or for certain diagnoses

[2] Routine symptom monitoring included as routine symptom monitoring using an appropriate tool or instrument for outpatients

[3] Specialist palliative care team referral rate calculated as the number of annual inpatient referrals to the SPCT as a percentage of the number of total annual hospital admissions

[4] N=32 (2 missings)

[5] MDTM Multidisciplinary team meeting

[6] Educational activities for fellows/trainees and nurses

[7] Possibility for residents and / or fellows hospital-wide or general practitioner trainees

CHAPTER 7

General discussion

The population of patients with incurable cancer continues to grow. These patients all require palliative care, and research shows that timely integration of palliative care into oncology hospital care leads to improved quality of life, reduced symptom burden, and less potentially inappropriate end of life care [1-8]. In the Netherlands a generalist-specialist model is applied for providing palliative care. In this model, hospital clinicians of the first responsible care team (i.e. generalists in palliative care) provide basic palliative care based on their standard training, including basic management of pain and symptoms and conversation about treatment goals [9]. These clinicians work together with specialists palliative care. In hospitals, these palliative care (PC) consultants are organised in specialist palliative care teams (SPCTs). PC consultants can support palliative care generalists in case of complex symptom burden on one or more dimensions (physical, psychological, social, and/or spiritual); by peer-to-peer consultation, or by referring patients and their families for a consultation. The timely integration of palliative care into standard care remains challenging within a generalist-specialist model. Studies show that, despite the clear benefits for its timely integration, palliative care is frequently initiated late in the disease trajectory [10] and SPCTs are often consulted only in the final phase of life [11].

Therefore, the overall aim of this thesis was to contribute to the timely integration of palliative care into oncology. In this chapter the main findings for each of our studies are presented and discussed in a broader perspective. In addition, methodological considerations and recommendations for clinical practice, research, education, policy and society are presented.

7.1 Main findings

To identify essential elements of timely integration of palliative care into oncology care, we conducted a Delphi study among a panel of experts that included clinicians working in hospitals, patient- and relative representatives (**Chapter 2**). The expert panel was questioned on four elements of timely integration of palliative care, namely: 1) identifying palliative care needs, 2) advance care planning (ACP) discussions, 3) routine symptom monitoring and 4) involving a PC consultant of the SPCT. They were asked about; who, when in the disease trajectory and by whom the four elements of timely palliative care were initiated in daily clinical practice. The experts agreed that in all patients with incurable cancer possible palliative care needs should be assessed, advance care planning discussions initiated and symptoms across all four dimensions monitored. A PC consultant should be involved at patient’s request or in case of symptom burden on multiple dimensions. When patients with incurable cancer have a life expectancy of less than three months they should be offered a consultation with a PC consultant, according to the experts.

Based on these findings, three recommendations were formulated on ACP, routine symptom monitoring and involving a PC consultant. In a pilot study (**Chapter 5**), these recommendations were found to be feasible in practice. Clinicians successfully implemented the recommendations in 50% of eligible patients, except for conducting ACP discussions which was achieved in only 49% of eligible patients. Patients who received care according to these recommendations generally reported the care as pleasant and helpful. Their satisfaction levels were comparable to those who received the standard of care, with one notable exception: patients whose social problems were monitored reported significantly higher satisfaction with their care.

Two interview studies showed that timely palliative care in daily clinical practice is individual and situational, with no one-size-fits-all approach. Identifying the right moment for introducing palliative care remains an ongoing challenge, even more so in haemato-oncological patients with unpredictable disease trajectories. To ensure the timely integration of palliative care, a two-track approach, a solid collaboration across care settings, between healthcare professionals within the hospital and in primary care, and being comfortable and skilled in the communicative tasks that accompany (palliative) care discussions are essential (**Chapter 3 and chapter 4**).

Analysing the provision of key components of palliative care showed that ACP and routine symptom monitoring in outpatients are not yet common practice in Dutch hospitals. SPCTs of hospitals that routinely screen the symptoms of outpatients had a higher number of referrals and were more likely to offer an internship in palliative care and provide palliative care education, compared to hospitals without routine symptom monitoring (**Chapter 6**).

7.2 Methodological implications

Study population

Involving the palliative care generalist

As this thesis examined the timely integration of palliative care in a generalist-specialist model, it was essential to include both the perspective of the generalist and the specialist palliative care clinician, limited to hospital care. Involving generalists in palliative care, i.e. oncology nurses and oncologists without expert knowledge in palliative care and with little experience with providing palliative care, proved challenging. This challenge was amplified by our recruitment method. For the Delphi study (**Chapter 2**) the regional advisors of the Dutch palliative care consortia[1] were asked to contact clinicians of three hospitals in their region which they considered to have good practices in timely integration of palliative care. The clinician contacted was often part of the SPCT. The convenience sampling method may have resulted in the inclusion of generalists in palliative care who knew the PC consultants and were aware of the SPCTs role and its added-value. For the interview study (**Chapter 3**), the researcher was present in the hospitals and could therefore reach out to several clinicians that were identified as palliative care generalists by PC consultants. However, bias could not be prevented and most generalists in palliative care that were recruited had an affinity with palliative care. They did not have the same expertise as a palliative care specialist but they may have had more knowledge of palliative care than other generalists. Some generalists that were approached stated that they did not know enough about palliative care and decided that, despite our explaining that deep knowledge about palliative care was not necessary, they did not want to participate. As a result, the findings of the interview study on how generalist palliative care is provided in a timely manner (**Chapter 3**) may reflect skills and communicational tact that palliative care generalists with an affinity for palliative care possess, but which might be more difficult to obtain by palliative care generalists without the same affinity. In addition, the recommendations that have been tested in the pilot study may be more difficult to integrate into daily clinical practice by palliative care generalists without basic knowledge of, and skills in, palliative care.

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[1] The Netherlands is divided into seven palliative care consortia. These are networks and partnerships of various national and regional organisations that focus on improving and implementing palliative care.

Patient recruitment

All patients with incurable cancer were eligible for inclusion in the studies of this thesis. Patients were recruited either by the Dutch Federation of Cancer Patients Organisations (NFK) or by their treating physician, nurse specialist or oncology nurse. Both recruitment methods may have introduced selection bias. The NFK is an umbrella organisation for 21 cancer patient organisations. They recruited patients from these patient organisations. These patients participate in research on a regular basis. Therefore, they were able to reflect on their disease trajectory and were more familiar with the way healthcare and palliative care are organised.

When patients are recruited by clinicians, gatekeeping can introduce selection bias. Clinicians may selectively recruit patients and exclude others based on personal judgement. Reasons for gatekeeping include concerns about patient burden, assumptions about patients' willingness to participate or reluctance to discuss palliative care with the patient [12]. Yet, participating in palliative care research can also provide patients with meaningful benefits, allowing them to make a valuable contribution despite their illness [13]. In our experience, patients did not seem reluctant to opt out of the research. Some patients in our study cancelled the interview due to unexpected events in their disease trajectory or because they had second thoughts, even when an appointment had already been scheduled.

Study methods

Delphi method

The Delphi method is widely used in healthcare research to reach consensus when the available knowledge is incomplete or when there is uncertainty about a specific topic [14]. However, there is still a considerable variety in the design of modified Delphi studies. A systematic review on Delphi studies showed that they varied in the number of rounds and their definition of consensus [15]. We aimed to be transparent about the steps we took in our Delphi study by following the proposed Conducting and REporting of DElphi Studies (CREDES) guidelines by Junger et al. (2017) on setting up and reporting a Delphi study in palliative care research. In our Delphi study, consensus was defined as an agreement of ≥70%, following an international Delphi on indicators of integration of oncology and palliative care programs by Hui et al. (2015). In the first round, characteristics (for who, when, and by whom) of elements of timely palliative care (identifying palliative care needs, ACP, symptom monitoring and the SPCT) were identified. For each element, the three to five most selected characteristics were turned into statements (e.g. 'ACP should be initiated for every patient with identified palliative care needs and metastases'). After analysing and discussing the second round results with the research group, we decided to formulate some additional statements for round three. These statements provided additional details on the characteristics of timely palliative care. After the third round, we analysed which characteristics in round two and three reached the threshold of ≥70%. This threshold is in line with other consensus studies in the field of palliative care [16, 17].

Survey

To assess clinicians' experience with the recommendations and patients' experience with the care in the pilot study they received a questionnaire that included validated measurements including the EORTC IN-PATSAT, as well as self-administered questions. There is a risk of low content validity when using self-administered questions. Additionally, the results might be more difficult to interpret. For example, 58% of patients stated that they found the consultation with a PC consultant pleasant. This provides some insight, but the word 'pleasant' ('prettig') might not be the most appropriate term for posing this question, as discussing future care wishes may not necessarily be pleasant. Although a representative of the Dutch Federation of Cancer Patients Organisations was involved in the development of the questionnaire, it might have been better to pilot test the self-administered questions with patient representatives.

Interview study

To gain a deeper understanding of the concept of 'timely palliative care', how it is delivered in a generalist-specialist model and amongst solid and haematological cancer patients two interview studies were conducted (**Chapter 3 and chapter 4**). Both studies used the constant comparative method to compare codes between researchers and to increase the validity. In hindsight, the methodological rigour could have been further strengthened by incorporating member checks during the coding process. The identified codes could have been shared with participating patients to confirm the accuracy of the findings.

7.3 Findings in a broader perspective

Timely integration of palliative care into oncology is essential to ensure that all patients receive high-quality and accessible care. Palliative care is, by nature, integrated care—delivered across care settings and involving collaboration between healthcare professionals and institutions. To support the right care in the right place for every patient, the Netherlands has introduced regional transformation plans for palliative care. These plans mark a shift from treating palliative care as something exceptional to fully embedding it within mainstream healthcare.

The 'Integraal Zorgakkoord' (IZA, Integral Healthcare Agreement) is a national agreement between the Dutch Ministry of Health, healthcare providers, insurers, municipalities, and patient organizations. It was developed to safeguard the future of healthcare in the Netherlands by promoting accessibility, affordability, and quality, in light of challenges such as an ageing population, rising healthcare costs, and staff shortages. The IZA transformation plans aim to embed palliative care more effectively within the standard healthcare system. They focus on proactive care planning, shared decision-making, and improved coordination across care settings, in line with the Dutch Quality Framework for Palliative Care.

Advance care planning

Advance care planning is an essential component of palliative care. A Delphi study of an international panel of experts defined ACP as 'the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate' [18]. Studies have shown that ACP reduces life-sustaining treatment, results in less invasive diagnostic and laboratory tests, and may increase SPCT referrals and the inclusion of advance directives in hospital files records [19-23]. However, ACP is not yet fully integrated into daily clinical practice within Dutch hospitals (**Chapter 6**). A recent cross-sectional survey of key members of the SPCTs of 58 Dutch hospitals showed that ACP is an integral part of the care policy for patients with palliative care needs in 37% of Dutch hospitals. 42% of respondents reported that ACP discussions are not conducted systematically [24]. A retrospective cohort study showed that the ACP tool had been initiated in 64.5% of 1230 patients with incurable cancer, and 17.6% of patients had a complete ACP document [21]. In our pilot study

(**Chapter 5**), the recommendation on ACP was the only one that did not meet the minimum application target of 50% of eligible patients.

Identified barriers for the integration of ACP within hospital care, lie on various levels. Barriers at the organisational level include lack of time, difficulty in accessing the ACP documents and staff shortages or staff rotation [25-27]. At the clinician level, barriers include a lack of knowledge and skills about ACP and the fear that ACP discussions will have a negative impact or diminish patients' feelings of hope (**Chapter 4**) [28, 29]. Barriers at the patient level include a lack of understanding of their disease and prognosis and a lack of knowledge about ACP and its use [30, 31]. It is important to note that Dutch general practitioners (GPs) perceive ACP as an important part of their job responsibilities [32]. Our studies were limited to hospital clinicians and therefore did not include the role of GPs.

To effectively integrate ACP into clinical practice and ensure timely discussions between patients and clinicians, several key elements need to be addressed. First, a standardised approach to documenting ACP discussions is essential. This documentation should be easily accessible to both patients and clinicians, across all healthcare settings. To promote this standardised documentation, a Dutch multidisciplinary project aims to make recorded outcomes of ACP discussions of patients with palliative care needs digitally accessible for healthcare providers and patients [33]. This project includes a feasibility pilot study and will lead to recommendations for national implementation. Second, ACP is a continuous and dynamic process that takes place across healthcare settings. Healthcare professionals in primary health care settings such as GPs often play a key role in conducting ACP discussions. Therefore, it is important to coordinate the process of ACP and its outcomes across different care settings. Third, a significant barrier frequently cited by clinicians is the lack of time and financial compensation. In response, several billing options have been developed. Including the possibility for GPs to bill a 'long consultation'. As part of the IZA's 'more time for the patient' ('meer tijd voor de patiënt') initiative, it is currently explored whether there are other ways of adequately funding GPs for ACP discussions [34]. The Dutch Healthcare Authority has also established a dedicated payment code for ACP in Dutch hospitals. While ACP discussions were previously included under regular consultations, beginning in 2025 clinicians are able to bill specifically for the ACP discussions. This dedicated time allocation and compensation structure is expected to enhance clinicians' ability to conduct timely ACP discussions. Fourth, evidence-based guidelines provide direction on when, for whom and how to initiate and conduct ACP discussions. These guidelines can facilitate the further timely integration of ACP into standard oncology hospital care. Fifth, healthcare providers should be knowledgeable about and skilled in conducting ACP discussions. Education and training are therefore essential. A growing number of courses for clinicians focus on ACP, including (e-)courses initiated by (regional) palliative care networks or by the second National Palliative Care Programme (NPPZII); a national program initiated by the Dutch Ministry of Health, Welfare and Sport that will run up to 2027. This program also encompasses a sixth key element for the timely integration of ACP, namely patient awareness. The process of ACP requires the active participation of patients. Patients should be aware of the concept of ACP and how it could benefit them. One of the priorities of the NPPZII is to raise patient awareness of palliative care, including ACP. The concept of ACP is very valuable and the process can be of great benefit for patients and patient-centred care, however, some points regarding the concept of ACP are important to consider. The first point is that ACP is no one-size-fits-all. Even with the proper documentation, reimbursement regulations and guidelines in place, it is not a checklist but a continuous and dynamic process, that spans various healthcare settings [35]. This process should be tailored to the values of the patient and their relatives. There are many different values that can differ between clinicians and patients and their relatives. Patients and their relatives may value not wanting to know about the disease and possible prognosis. This requires clinicians to ask different questions and discuss different topics (e.g. not discussing possible physical symptoms that may occur in the future, but discussing which family member can be consulted in the care of the patient if the patient is uncapable to make care decisions). Or clinicians may struggle with patients or relatives who insist on treatment despite a lack of clinical benefit. The use of language can be of great importance in navigating these challenging situations. Evidence shows that communication quality significantly impacts patients experiences. A systematic review on harmful communication behaviours in cancer care showed that patients and relatives felt it was harmful when information was provided in an inappropriate way, such as being rude, cold and uncaring [36]. Moreover, effective communication is characterised by 'open and honest information' and 'empathy' in a recent systematic review [37]. These findings align with our interview study results (**Chapter 2**), where patients emphasised the importance of appropriate wording when introducing palliative care and expressed appreciation for sincere conversations.

Routine symptom monitoring

Routine symptom monitoring should be an integral part of ACP and enables early detection of adverse effects and complications, allowing healthcare providers to intervene promptly before symptoms become severe. It has been shown to improve patients' quality of life by ensuring better symptom management and reducing ad hoc interventions, emergency department visits and hospitalizations [38-41]. In addition, the results of symptom monitoring can be used to discuss patients' needs and preferences for care, to support the process of shared decision making and to foster care decisions (e.g. dose reduction, change of treatment, or foregoing a specific treatment option) that are in line with what the patient considers important.

Despite these clear benefits of symptom monitoring, the implementation of (electronic) patient-reported outcomes ((E)PROS) into the workflow of standard cancer care has been slow. Challenges to implementation lie in several areas. Technical and infrastructural challenges include selecting the optimal system, either licensing an EPRO system or using an assessment tool built into the Electronic Medical Record (EMR), knowing which items to collect, at what time and for whom, software functionality, measured outcomes, and needing to modify the workflow [42-44]. Challenges in the domain of clinicians include clinicians' reluctance to integrate (E)PROS, disruption of workflow, increased workload, and frustration and disappointment with increased workload without seeing the benefit to oncology care [45-49]. Despite these barriers, research also shows that patient adherence to EPROs is high, demonstrating their willingness to complete questionnaires about their symptoms [38, 49]. Yet, for effective implementation, it remains important to improve patients' digital and health literacy and to increase the perceived benefits of completing questionnaires [50, 51].

An example of a good practice comes from a recent study in which a remote symptom monitoring pathway was implemented in 33 oncology centres in France and Belgium. Patient adherence reached 82%, with high satisfaction rates among both clinicians and patients. They attributed this high rate to a structured and well-defined implementation process, the involvement of many stakeholders in co-designing the remote patient monitoring system and the short feedback and evaluation loop for patients with a median of 13 hours and 41 minutes [44]. Another study among patients with lymphoma showed similar results that a high number of patients wished to receive PRO feedback and valued being able to compare their own scores to those of a lymphoma reference cohort [52].

Symptom monitoring should be focused on the physical, psychological, social, and spiritual suffering patients can encounter, as described in the definition of palliative care. Cicely Saunders, the founder of modern hospice care and responsible for establishing the discipline of palliative care, introduced the term 'total-pain' to describe patients' experience of pain as multidimensional, including all four dimensions: physical, psychological, social and spiritual [53]. One of the most studied physical symptoms in cancer patients is pain [54, 55]. Measuring (physical) pain remains challenging due to its subjectivity and its connectedness to other domains, e.g. through pain resulting in pain-related distress [56, 57]. In addition, patients with incurable cancer have reported non-pain symptoms such as fatigue and dyspnoea more often than pain [58]. Yet, non-pain symptoms often remain untreated while they negatively influence patients' quality of life [59]. An ethnographic study with participant observation at an oncology department of a university hospital found that whilst nurses picked up on patients' cues of spiritual issues, they did not explore them [60]. These studies suggest that while physical symptoms are often monitored and explored, the psychological, social and spiritual dimensions are often overlooked and unexplored. Studies have also found that cancer patients and their carers report unmet psychosocial needs [61, 62]. Tools such as the Utrecht Symptom Diary-4 Dimensional (USD-4D) and modified versions of the Edmonton Symptom Assessment System (ESAS) are tools that include all four dimensions of QoL and are very useful for a holistic assessment of patients well-being [63-65].

Besides the importance of a holistic view and approach to suffering, there are other elements to consider for improving further integration of routine symptom monitoring. Palliative care is integrated care, therefore it is imperative that EPROS can be interpreted and utilised across healthcare settings. A crucial step involves the mapping of outcomes from different instruments, including the USD-4D, EORTC QLQ-C30, the Edmonton Symptom Assessment System, the Functional Assessment of Chronic Illness Therapy–Palliative Care Scale, and the Patient-Reported Outcomes version of the Common Terminology

Criteria for Adverse Events. Various studies have focused on mapping datasets, including mapping Patient Reported Outcomes (PROMs) to the World Health Organization's International Classification, or by developing algorithms [66, 67]. Consistent outcome measures, even with different instruments, ensure continuity of care across healthcare settings, but are also essential for research into the relationship between different treatments and symptoms in different patient populations. This, in turn, can inform future healthcare.

Findings presented in this thesis emphasise the importance of language when introducing palliative care (**Chapter 2**). However, choosing the right words can be challenging. Especially since some words have no literal translation in the Dutch language. While the English words 'anxiety' or 'distress' are commonly used in everyday language, the Dutch language lacks precise equivalents of these prevalent emotions [68]. The Dutch language did adopt the word 'stress', but it has only been included into the leading dictionary of the Dutch language in 1961 [69]. When looking up 'anxiety' and 'distress' in the leading dictionary of the Dutch language, the Van Dale Great Dictionary of the Dutch Language, the translations feel inadequate (anxiety translates to 'bezorgdheid, ongerustheid, vrees' and distress to 'leed, verdriet, zorg, nood, armoede, gevaar, nood'). These suggested words are not commonly used in everyday Dutch speech. A study on the semantic of emotion showed that the meaning of emotion terms vary greatly across cultures, and that in certain languages 'anxiety' was closely related to 'fear', while in others it was more closely related to 'grief' and 'regret' [70]. It is challenging to determine the closest related Dutch word. This linguistic limitation may result in an underreporting of emotional symptoms. A possible solution may be to develop and use tools that combine text, audio and even visual prompts to convey a storyline or elicit a feeling that does not directly translate to Dutch, yet can be recognised and explored by patients and clinicians.

Language is also an important element for making symptom monitoring more inclusive. In the Netherlands, 16% aged between 16 and 65 have a low language proficiency and 35% of Dutch people have limited health literacy [71, 72]. PROMs should be inclusive; applicable and accessible to patients with different diagnoses, ages, cultural backgrounds, languages and levels of health literacy. A recently developed conceptual framework called the Accessibility, Relevance, and Impact conceptual framework of digital inclusivity for health information systems can support and strengthen the inclusivity of digital tools [73]. The

Dutch Cancer Society (KWF) recently awarded grants to several projects that study the impact of culture, social-economic position, health literacy and sexual orientation on routine symptom monitoring.

Specialist Palliative Care Team in Dutch hospitals

In 2014 the World Health Organisation published a report acknowledging and emphasising the importance of palliative care, due to the growing evidence of its benefits and the rising prevalence of non-communicable diseases, combined with a worldwide aging population [74]. Consequently, the American and European oncology societies have issued recommendations on the integration of palliative care into oncology care [75, 76]. In 2014, the SONCOS standardisation report, a national report with national oncology standards, stated that from 2017 onwards, every Dutch hospital should have a multidisciplinary palliative care team. When this standardisation report was published, the way in which the specialist palliative care teams (SPCTs) were organised varied greatly from hospital to hospital. Over the years, some hospitals were able to establish dedicated and well-integrated SPCTs with a high level of palliative care expertise. SPCTs are also increasingly collaborating with primary care providers and providing care to patients at home [77].

A study showed that SPCTs with a higher referral rate were more likely to have more timely referrals, to exist longer, to have a dedicated outpatient clinic, and to provide palliative care education outside their own hospital [10]. However, this study also showed that most SPCT referrals occur quite late in the disease trajectory, they occur mostly in the last 3 months to four days prior to death. Our interview study with haematology clinicians (**Chapter 4**) illustrates clinician-perceived barriers for involving a PC consultant, such as the unpredictable disease trajectory and the wide range of treatment options, which make it difficult for clinicians to find the most appropriate and timely moment to introduce the SPCT. Other known barriers from the perspective of clinicians for (timely) SPCT referral include stigma/presumptions about palliative care and the need to control and coordinate the care process for their own patients, being too optimistic about the prognosis, the fear of taking away patients' hope and a personal reluctance to discuss palliative care-related topics [78-81]. An interview study among oncology patients found that they experienced an introduction to palliative care early in their disease trajectory as confrontational yet beneficial

[82]. The interview studies (**Chapter 3 and 4**) also emphasize the importance of creating a clear delineation of roles between the first responsible care team and the palliative care consultant, and how the open and supportive attitude of the PC consultants fosters a solid collaboration between the palliative care generalists and the SPCT. Another aspect that can promote timely SPCT involvement is the development of guidelines on when to refer a patient. These guidelines should be specific to the generalist-specialist model, in which the primary care team is expected to provide basic palliative care and the SPCT is available as an additional layer of support. Guidelines should elaborate on the definition of complex care needs and acknowledge the individual and situational character of complexity.

In addition to clinician barriers, patients and their relatives also experience barriers. Patients tend to have limited knowledge and awareness regarding palliative care, and often equate it with end-of-life care [81, 83]. Results of our interview study (**Chapter 3**) suggest that a clear explanation of palliative care and the SPCT makes patients less reluctant toward palliative care. We also found that patients consider it important to be informed about the SPCT in a timely manner. This did not necessarily mean that they wanted to be referred to a palliative care consultant, but knowing about the team gives them the opportunity to request their involvement if they wish. By informing patients about palliative care options and available palliative care providers in various care settings (GPs, palliative home care teams and SPCTs), patients can make informed decisions to request for palliative care in the most appropriate setting for their situation.

7.4 Recommendations on timely integration of palliative care

Recently, all scientific organisations involved with the care for patients with a malignancy, among which the Dutch Association of Medical Oncologist (NVMO), Dutch Association of Radiotherapist in Oncology (NVRO), Dutch Association of Oncological Surgery (NVvH) and Dutch Nursing Society (V&VN), in collaboration with NFK and GPs, drafted three recommendations on timely integration of palliative care into oncology hospital care in the Netherlands.

1. **Advance Care Planning** (ACP) is offered to all patients with incurable cancer in a timely manner. These are discussions about life goals, choices and which care fits them now and in the future. Discussions are conducted (again) in the event of increased symptom burden, a life expectancy of <1

year (identified using the Surprise Question (SQ) 'Would I be surprised if this patient dies within 12 months?') and/or a change in line of treatment. To promote continuity of care, the division of roles in and outcomes of proactive care planning conversations are coordinated with the GP or institution physician(s) involved and recorded in the electronic health record.

2. **Routine symptom monitoring** is an integral part of ACP**.** Attention should be given to symptom monitoring and management in the four dimensions (physical, psychological, social and spiritual), at least, for all patients with a life expectancy of <1 year (identified using the SQ). The outcomes of the symptom monitoring in these four dimensions and treatment decisions are recorded in the electronic health record. Preferably, this is done periodically and systematically.
3. Involvement of the **multidisciplinary specialist palliative care team** is considered, at least, in complex problems such as symptom burden on multiple dimensions, and/or when requested by the patient.

These recommendations have been integrated into the national SONCOS standardisation report. The recommendations provide guidelines on when, and for whom, to initiate an essential element of timely palliative care [84].

7.5 Recommendations for clinical practice, research, education, policy and society

7.5.1 Recommendations for clinical practice

Implementing guidelines in clinical practice across care settings

Clinicians and institutions should adopt and implement evidence-based guidelines to ensure the timely integration of PC and its key components including ACP and symptom monitoring. Guidelines regarding terminology and integrating ACP in daily clinical practice, support clinicians in knowing when and how to conduct ACP discussions with patients with palliative care needs in various care settings.

Integrate (Electronic) Patient Reported Outcomes in daily clinical practice

(Electronic) Patient Reported Outcomes ((e)PROMS) should be integrated into daily clinical practice. Most optimal would be real-time monitoring with a short feedback loop in which patients' outcomes are reported back to them by a clinician shortly after completing the questionnaire. The feedback given by clinicians should be a discussion between the clinician and the patient about what their outcomes mean and how the patient can be supported in relieving their symptoms. This substantive feedback and discussion will make patients more inclined to fill out future questionnaires.

Evolving SPCTs: transforming from direct service to empowering generalists

As studies presented in this thesis show, it is important that SPCTs adopt a more critical approach to consult request and not merely proving their additional worth by doing as many consults as possible (e.g. advising treating physicians on palliative sedation rather than performing it directly). This is in line with previous findings of a national project in which a broad group of stakeholders established quality standards for palliative care, which resulted in the publication of the Netherlands Quality Framework for Palliative Care. One of the key points of the Quality Framework is that consultants of the SPCT can be asked for advice or support in case of complexity that exceeds the expertise and skills of palliative care generalists [35]. Since SONCOS issued the guidelines on the SPCT obligation for every hospital providing cancer care, eight years ago, many teams have evolved from raising awareness about palliative care and accepting every consultation request, to focusing on educating and empowering palliative care generalists and being more critical on which consultation request to accept. This process is important to create a sustainable generalist-specialist care model. It enables palliative care generalists to provide basic palliative care themselves, and thereby increasing their skills and knowledge, while allowing palliative care specialists to contribute their knowledge where it is most needed, truly becoming an extra layer of expertise. In this way, palliative care becomes an integral part of oncology care.

Empowering patients and families

Clinicians should provide patients and their families with the necessary resources to prepare for ACP conversations. Conducting ACP discussions requires an active and involved attitude of patients. Patients should feel empowered to bring up ACP if their health care providers do not initiate an ACP discussion, they should feel knowledgeable on what topics they can discuss and should feel equipped to express their care wishes and worries. In the research project ‘In conversation with citizens’ (‘In gesprek met de burger’) a format has been developed enabling GPs to host information meetings for their patients [85]. In addition, a toolkit was developed allowing other healthcare professionals to organise these meetings themselves. Other informative and helpful digital tools include the website Overpalliatievezorg.nl, where evidence-based information and guidelines have been made understandable for patients and relatives. Through webinars, infographics, videoclips, and links to online decision aids for exploring your care and treatment wishes, patients can learn about ACP and prepare themselves for the discussion.

7.5.2 Recommendations for research

Determining appropriate outcome measures

Future research should focus on identifying the most appropriate outcome measure for palliative care and its components such as ACP. Appropriate and uniform outcome measures allow for effective routine symptom monitoring, data sharing and supports quality of care. 'Overall wellbeing/quality of life', 'pain' and 'information needs and preferences' have been suggested outcome-based domains for palliative care [86]. The effect of ACP remains largely unknown, and discussions continue over which outcome measure is most appropriate [23, 87, 88]. An international trial found no impact on quality of life but suggested that, as an international Delphi study indicated, quality of life may not be the best measure for assessing the effects of ACP [18, 22]. Researchers have proposed goal-concordant care as a more suitable outcome measure, but solid evidence is still lacking [88]. Within the National Palliative Care Programme (NPPZII) 16 indicators for palliative care have been identified, that can be used to assess the quality and accessibility of palliative care in the Netherlands and are helpful in the process of determining outcome measures [89].

Using real-world data for assessment of ACP integration and outcomes

Real life data should be used for assessing the effect of ACP, especially since trial settings may have a suboptimal integration of ACP into daily clinical practice, causing patients to have fewer ACP discussions than intended, possibly influencing the results [22]. Using real-world data would allow future research to monitor the integration of ACP and could help in identifying appropriate outcome measures. A European study has elaborated on the importance and future perspective of using routinely collected health and social care data to improve palliative care [90]. In addition, real-world data are also helpful in assessing the extent to which the guidelines incorporated in the SONCOS standardisation report are applied in daily clinical practice, as well as their effects. Using real-world data makes it easier to adapt to daily clinical practice. The results will allow for systematic reassessment and adjustment of the recommendations on timely palliative care in the coming years.

Using technology in symptom monitoring: ensuring access for all

Future research should focus on how innovative digital communication technologies can improve the implementation of symptom monitoring. Current technological advancements offer opportunities for routine symptom monitoring by making symptom monitoring less time consuming, less labour-intensive and more feasible [91]. Research on novel technologies and implementing symptom monitoring should be inclusive and equitable and include underserved groups, including patients with a barrier to using digital tools, patients with lower social economic positions, low health literacy, those who do not speak the language of the country in which the research is taking place, or those with different cultural backgrounds than American or western-European [92].

Defining complexity in palliative care: a framework for specialist PC

To further promote palliative care to be an integral part of oncology care, focus should be on equipping palliative care generalists so they feel skilled and confident enough to provide palliative care. In addition, it is important to know how many palliative care specialists are needed. This requires clear criteria of when to involve PC consultants. A common criterion is: in case of ‘complexity’. Our third recommendation for timely integration of palliative care also uses complex problems as a trigger for involving a PC consultant. As a guideline and based on the findings of the Delphi study (**Chapter 2**), the recommendation states that complex problems include symptom burden on multiple dimensions**.** While this gives a direction of what complexity entails, an exhaustive definition has not yet been formulated. A systematic review of classification systems determining complexity in patients with palliative care needs found no standard manner to determine complexity and states that it is a phenomenon defined through clinical reasoning [93]. Future research should therefore focus on operationalising complexity by specifically defining for which patients, with what symptom burden, on which dimensions, with what additional issues, the SPCT should be involved. With a standardised definition of ‘complexity’ the number of patients with complex palliative care needs can be assessed, thereby enabling a more precise calculation of staffing needs for the SPCT.

7.5.3 Recommendations for education

Palliative care in clinical curricula and continuous training

In striving towards a fully optimised generalist-specialist model, all healthcare providers should be educated on palliative care so they feel equipped, skilled and confident to initiate and conduct ACP discussions, monitor symptoms on all four dimensions and discuss the outcomes with patients. Palliative care and its elements should therefore be embedded in clinical curricula. In 2024 a motion was passed by the Dutch House of Representatives, which recommended that the existing clinical curricula should be examined and that it should be explored how palliative care can be given a structural place within these curricula. In addition, continuous training on palliative care elements such as ACP should be offered. These trainings should be tailored to and suited for generalists and the settings in which they provide palliative care.

National educational initiatives for continuous training on palliative care

Palliative care should be integrated into continuous training to better educate generalists. Over the last years many tools have been developed to foster the education on palliative care. The Netherlands Organisation for Health Research and Development (ZonMw) funded the Improving Education in Palliative Care (O^2PZ) project. In this project tools for educators have been developed, as well as a frameworks with which education developers can further improve the education on palliative care. Another recent initiative to further improve generalist palliative care is the launch of a national palliative care training program for healthcare professionals in oncology, funded by KWF. A national, uniform continuing education program has been developed and offered, with only limited cost for clinicians, with the aim of having trained 3500 clinicians by December 2025. In addition, an improved level of knowledge about palliative care among teachers and trainers of MBO, HBO and WO courses and additional and refresher courses is needed. Therefore, a teacher training has been developed and implemented [94].

7.5.4 Recommendations for policy

Integrating palliative care into national policy

Palliative care should be seen as an integral aspect of (oncology) care. In the Netherlands, through the IZA, various stakeholders have committed themselves to making healthcare care accessible and feasible, now and in the future. It is important that these stakeholders commit to the integration of palliative care into standard care and include a vision for the integration of palliative care in their policy. This should be implemented, not as a separate aspect of care but as an integral part of standard care.

Using data insights for quality improvement of palliative care

Data insights should be used to inform policy makers (national and institutional) to evaluate and improve the quality of palliative care and guide their policy. Great efforts have been made to match different, existing, data in order to gain a perspective on the current state of palliative care in the Netherlands. These efforts include an interactive tool that shows potential palliative care needs at different levels (national and regional), developed by IKNL (Kerncijfers behoefte aan palliatieve zorg) and several factsheets from a national project aimed at improving data-driven learning in palliative care [95]. Another example is the Oncological Care Monitor (Monitor Oncologische Zorg), an online application that is updated monthly and includes information on all cancer types, diagnostics and treatments. Hospitals can access their own data and compare it to that of other hospitals. Since 2022, this monitor also includes information on palliative care and end-of-life care. In order to use existing data for quality improvement, it is important that data is recorded clearly and in a structured manner at the source. An information standard is being developed for advance care planning. In addition it is important to link with (inter)national developments in the field of data availability, such as the Health Data Access Body, and to follow legislation such as the European Health Data Space [96, 97].

7.5.5 Recommendations for society

Building public awareness: a social approach to palliative care awareness

Timely palliative care requires a societal shift; therefore, investments should be made to raise public awareness about palliative care. One of the main barriers to the timely integration of palliative care is the reluctance of patients who do not fully understand what palliative care is. Initiatives to raise awareness of palliative care are taking place in different countries and at an international level, such as the international World Hospice and Palliative Care Day, the Dying Matters Awareness Week in the United Kingdom, the National Palliative Care week in

Australia and the National Hospice and Palliative Care Month in the United States. In the Netherlands PZNL recently initiated a social awareness campaign titled ‘Living until the end’ (Leven tot het Laatst). Future social awareness campaigns should use a target group approach to reach different groups of people, to encourage people (not just patients) throughout the nation to discussions about illness, suffering and death and quality of life with their friends and families. In addition, promoting literacy in death and grief should become a key aspect of public health and palliative care [98, 99].

Reframing the language of illness and death

Linguistic frameworks profoundly influence how patients conceptualise their illness experience and way of dying. For example the Dutch medical term for having exhausted all treatment options (‘uitbehandeld’) may give patients the feeling that all care is being withdrawn. In case of an incurable disease, certain treatments may be withdrawn, but never the care [100]. In addition, terms such as ‘fighting’ a ‘battle’ to ‘beat’ the disease suggests that foregoing treatment options means to lose or give up. Thus, we need new frameworks to discuss incurable illnesses and death. Research has recognised that violent metaphors seem to imply that patients have certain personal responsibility in their disease trajectory, and should therefore no longer be used in the context of cancer [101]. Philosopher and professor of public philosophy Marli Huijer explains that the focus in periods characterised by illness and a (slowly) approaching death lies on giving meaning to having a disease, suffering and dying. She gives several recommendations on how we, as a society, can contribute to giving meaning to these inevitable aspects of life, including the reinforcing of social networks between the older and younger population, so they can learn from each other and can reassess the value of youth and the elderly. She also advocates for providing meaningful stories instead of numbers and statistics only, e.g. in movies, literature or the news, that reflect how people, their families and loved ones deal with being sick, mortality and giving meaning [102]. This perspective aligns with a report of the Lancet commission that offers five principles of a new vision on death and dying, three of which include: dying should be seen as more than merely physical but rather a relational and spiritual process, that conversations and stories about everyday death, dying and grief should become common, and that death should be recognised as having value [99].

Reconceptualising timeliness: expanding the concept

We have to reconceptualise timeliness in palliative care. Most literature discusses ‘early palliative care’, meaning an early moment to refer patients to the SPCT. ‘Early’ can refer to a diagnosis as a benchmark (e.g. within two months after diagnosis of advanced cancer [3, 5]), prognosis (e.g. estimated prognosis of 6-24 months) [6], or a combination of those two (estimated prognosis of < 12 months and within 3 months after diagnosis [103], clinical prognosis of 6-24 months and within 2 months after diagnosis [104]). Chronos and Kairos an ancient Greek distinction used to discuss time, can help us in reconceptualising timeliness. Chronos refers to time as objective, measurable, and as a quantity of duration (age, minutes, speed), whereas Kairos refers to a moment when something is appropriate, when something can only happen ‘at this time’ because the opportunity to do it another time might not recur [105]. The Chronos clock is deeply rooted into Dutch society, our educational system and in our healthcare, as it allows us to control our work, however, it also makes us see time and development as linear [106]. Our findings suggest that timely palliative care in a generalist-specialist model is an interplay between Chronos and Kairos. Introducing palliative care soon after the diagnosis of incurable cancer, using the right terminology, while being clear and sincere yet sensitive and personal, is proactive and follows the Chronos clock. However, the gradual approach that follows, in which certain topics are raised when it seems appropriate, follows a Kairos clock.

Timely palliative care means that palliative care is initiated based on a patients’ needs and delivered at a time that is optimal for that patient [78]. This requires clinicians to follow both the Chronos and Kairos clocks. The Chronos clock, with specific triggers to integrate palliative care, conduct an ACP discussion, start symptoms monitoring or to refer a patient to a PC consultant, ensures palliative care is not integrated too late. However, all aspects of palliative care are dynamic processes that benefit from following the Kairos clock, which puts patients’ needs at the centre.

7.6 Conclusion

Timely palliative care in oncology care includes a timely initiation of ACP discussions, routine symptom monitoring across all four dimensions (physical, psychological, social and spiritual) and a timely consideration of the involvement of a palliative care specialist. In Dutch hospitals however, all three components are not yet common practice. The recently adopted recommendations on timely integration of palliative care can support the timely initiation of these key components of palliative care. The recommendations state that: 1) proactive care planning discussions should be initiated for all patients with incurable cancer, 2) attention should be paid to routinely monitor symptoms in all four dimensions (physical, psychological, social and spiritual), at least, for all patients with a life expectancy of <1 year, and 3) involving a palliative care consultant should be considered, at least, in case of complex problems such as symptom burden on multiple dimensions, and/or when requested by the patient.

Providing timely palliative care following these recommendations is feasible in daily clinical practice. However, since timely palliative care is highly individual and situational and does not have a one-size-fits-all approach, the search for a timely and the most optimal moment is an ongoing challenge. A gradual and proactive approach, together with a solid collaboration between healthcare professionals within hospitals and across care settings, facilitate this process of being timely.

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CHAPTER 8

Summary of the thesis (in Dutch)

Wereldwijd stijgt het aantal patiënten met ongeneeslijke kanker. Voor patiënten met ongeneeslijke kanker en hun naasten is tijdige integratie van palliatieve zorg van groot belang. Palliatieve zorg is zorg gericht op de kwaliteit van leven van patiënten en hun naasten door het voorkomen en verlichten van lijden middels het signaleren en behandelen van problemen van fysieke, psychische, sociale en spirituele aard. Tijdige integratie van palliatieve zorg in de oncologie heeft bewezen voordelen, zoals verbeterde kwaliteit van leven, verminderde symptoomlast en verhoogde zorgtevredenheid. Ondanks de aangetoonde meerwaarde wordt palliatieve zorg in de dagelijkse praktijk suboptimaal en laat geïntegreerd. Het doel van dit proefschrift was om bij te dragen aan de tijdige integratie van palliatieve zorg in de oncologische zorg door een combinatie van kwantitatief en kwalitatief onderzoek. De vijf subdoelen waren:

1. Consensus bereiken over essentiële elementen van tijdige integratie van palliatieve zorg in de oncologische zorg onder zorgprofessionals, patiënten met ongeneeslijke kanker en naastenvertegenwoordigers
2. Onderzoeken wat oncologische zorgprofessionals en patiënten met ongeneeslijke kanker onder ‘tijdige palliatieve zorg’ verstaan en hoe deze wordt geleverd in een generalist-specialist model
3. Aanbevelingen ontwikkelen voor de tijdige integratie van palliatieve zorg in de oncologische ziekenhuiszorg in Nederland
4. De haalbaarheid van deze aanbevelingen beoordelen in vier Nederlandse ziekenhuizen
5. Het analyseren van de kernelementen van palliatieve zorg in de dagelijks praktijk in Nederlandse ziekenhuizen

In **hoofdstuk 2** worden de resultaten van een Delphi studie onder een expertpanel bestaande uit zorgprofessionals, patiënten met ongeneeslijke kanker en naastenvertegenwoordigers beschreven (subdoel 1). Het expertpanel is gevraagd naar essentiële elementen van tijdige integratie van palliatieve zorg. Zij bereikten consensus over vier essentiële elementen: (1) identificatie van palliatieve zorgbehoeften, (2) proactieve zorgplanning (PZP) gesprekken, (3) routinematige symptoommonitoring en (4) het betrekken van een consulent van het specialistisch team palliatieve zorg. De experts waren het erover eens dat bij alle patiënten met ongeneeslijke kanker: moet worden beoordeeld of zij mogelijke palliatieve zorgbehoeften hebben, PZP gesprekken moeten worden geïnitieerd, en symptomen op alle vier de dimensies moeten worden gemonitord. Ook stelden de experts dat een consulent van het specialistisch team palliatieve zorg moet worden betrokken als patiënten hierom vragen en/of bij klachten op meerdere dimensies. Tot slot vonden de experts dat patiënten met een levensverwachting van minder dan drie maanden een gesprek met een consulent van het specialistisch team palliatieve zorg aangeboden zouden moeten krijgen.

In twee kwalitatieve interviewstudies onderzochten we tijdige integratie van palliatieve zorg binnen de medische oncologie en (hemato)oncologie (subdoel 2). **Hoofdstuk 3** laat de resultaten van een interviewstudie zien waaruit bleek dat tijdige palliatieve zorg individueel en situationeel is, geen one-size-fits-all. Hierdoor blijft het identificeren van het juiste moment om palliatieve zorg te introduceren een voortdurende uitdaging. Essentieel voor het tijdig integreren van palliatieve zorg waren proactief handelen, een sterke samenwerking tussen zorgverleners en sensitieve communicatie. Daarnaast benadrukten zorgverleners het belang van een stapsgewijze benadering, waarbij onderwerpen gerelateerd aan palliatieve zorg geleidelijk geïntroduceerd en besproken worden met patiënten en naasten.

Hoofdstuk 4 geeft inzicht in de perspectieven van hematologische zorgprofessionals op de integratie van palliatieve zorg voor patiënten met hematologische maligniteiten. Barrières voor het tijdig integreren van palliatieve zorg waren het onvoorspelbare ziekteverloop en de mogelijkheid tot meerdere behandelingsopties. Zorgprofessionals vonden het lastig om het juiste moment te vinden voor het introduceren van palliatieve zorg omdat de conditie van patiënten met hematologische maligniteiten lang heel goed kan zijn maar plotseling kan omslaan en verslechteren. Het toepassen van het tweesporenbeleid waarbij curatieve en palliatieve zorgpaden naast elkaar bestaan kan de integratie van palliatieve zorg bevorderen.

Op basis van de resultaten uit hoofdstuk 2 en 3 zijn aanbevelingen voor de tijdige integratie van palliatieve zorg opgesteld (subdoel 3). De aanbevelingen betreffen proactieve zorgplanning, routinematige symptoommonitoring op de vier dimensies en het betrekken van een consulent van het specialistisch team palliatieve zorg. Om de haalbaarheid van deze aanbevelingen te beoordelen was een pilot studie opgezet waarin deze aanbevelingen werden toegepast in de dagelijkse praktijk van vier Nederlandse ziekenhuizen (subdoel 4). De resultaten hiervan staan beschreven in **hoofdstuk 5**. Zorgprofessionals waren in staat om de aanbevelingen bij ongeveer de helft van de patiënten met ongeneeslijke kanker toe te passen. Patiënten die zorg ontvingen volgens de aanbevelingen vonden deze zorg over het algemeen prettig en behulpzaam. De tevredenheid met zorg was vergelijkbaar met die van patiënten die reguliere zorg ontvingen. Patiënten waarbij problemen op de sociale dimensie werden gemonitord rapporteerden een significant hogere mate van tevredenheid van zorg dan patiënten die aangaven dat er niet was gevraagd naar problemen op de sociale dimensie. De pilot studie toonde aan dat het haalbaar is om de aanbevelingen toe te passen in de klinische praktijk en dat ze kunnen bijdragen aan een betere kwaliteit van zorg voor patiënten met ongeneeslijke kanker.

In **hoofdstuk 6** analyseerden we twee kernelementen (proactieve zorgplanning en routinematige symptoommonitoring) van palliatieve zorg in Nederlandse ziekenhuizen en welke factoren hiermee samenhangen (subdoel 5). Proactieve zorgplanning en routinematige symptoommonitoring zijn nog niet optimaal, ziekenhuis-breed, ingebed (respectievelijk 12% en 59%). Ziekenhuizen die symptomen van poliklinische patiënten routinematig monitoren hadden een hoger aantal verwijzingen naar het specialistisch team palliatieve zorg en boden vaker een stage voor artsen in opleiding in palliatieve zorg en palliatieve zorgonderwijs aan.

Hoofdstuk 7 omvat de algemene discussie van dit proefschrift met de belangrijkste bevindingen, de methodologische overwegingen en de aanbevelingen voor de klinische praktijk, toekomstig onderzoek, onderwijs, beleid en maatschappij. De conclusie is dat het tijdig initiëren van proactieve zorgplanning en symptoommonitoring op de vier dimensies en een tijdige overweging om een consulent van het specialistisch team palliatieve zorg te betrekken voor patiënten met ongeneeslijke kanker en hun naasten, essentiële elementen zijn van tijdige palliatieve zorg. Deze elementen zijn nog niet volledig ingebed in de Nederlandse ziekenhuizen maar moeten onderdeel gaan uitmaken van de reguliere oncologische zorg. De recent opgenomen aanbevelingen voor tijdige integratie van palliatieve zorg in het SONCOS normeringsrapport 2025 kunnen hierbij helpen.

Deze aanbevelingen stellen dat:

1. proactieve zorgplanningsgesprekken moeten worden aangeboden aan alle patiënten met ongeneeslijke kanker
2. er aandacht moet zijn voor symptoommonitoring en symptoombehandeling op de vier dimensies (fysiek, psychisch, sociaal en spiritueel), in ieder geval, voor alle patiënten met een levensverwachting van <1 jaar
3. het betrekken van het specialistisch team palliatieve zorg in ieder geval moet worden overwogen bij complexe problematiek, zoals symptoomlast op meerdere dimensies, en/of als de patiënt dit wenst

Het tijdig integreren van palliatieve zorg volgens deze aanbevelingen is haalbaar in de dagelijkse klinische praktijk. Omdat tijdige palliatieve zorg zeer individueel en situationeel is, blijft de zoektocht naar een tijdig en optimaal moment een constante uitdaging. Een stapsgewijze en proactieve benadering, een continue afstemming tussen de patiënt en naasten en zorgprofessionals, samen met een sterke samenwerking tussen zorgprofessionals binnen ziekenhuizen en transmuraal, helpen bij het tijdig integreren van palliatieve zorg in de reguliere oncologische zorg.

APPENDICES

Curriculum vitae

Carly Heipon (Zutphen 1992) grew up in Lochem, the Netherlands. In 2010, she graduated from secondary school (Isendoorn College, Zutphen). She then started a Bachelor's in Interdisciplinary Social Science at Utrecht University. After completing her degree in 2014, she traveled through Indonesia for six months. Upon return she enrolled in the Master's program in Anthropology and Development Sociology at Leiden University, which she completed in 2016.

After obtaining her Master's degree, she spent a year living in Taipei, Taiwan working as an English teacher. She subsequently worked for various government institutions in the Netherlands and spent a year traveling throughout Asia. In 2020, she began a post-Bachelor in Loss, Grief and Dying Counseling, and obtained her diploma in 2022.

In 2021, she started working as a junior-researcher and PhD-candidate at the Netherlands Comprehensive Cancer Organisation (Integraal Kankercentrum Nederland, IKNL) within the palliative care research team. She currently works as a postdoctoral researcher at Leiden University Medical Center in the department of Medical Decision Making.

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