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Original Article

The self-perceived palliative care barriers and educational needs of clinicians working in hospital primary care teams and referral patterns: lessons learned from a single-center survey and cohort study

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Background: Within the generalist-plus-specialist palliative care model, palliative care is mainly provided by nurses and physicians of hospital primary care teams. Palliative care consultation teams (PCCTs) support these clinicians in adequately caring for patients with advanced illnesses. Our team started in 2012. The aim of this study was to assess the self-perceived barriers, educational needs and awareness of available palliative care support options among our hospital primary care teams. In addition, palliative care referral patterns were evaluated.

Methods: Single-center mixed methods study. Outcomes of two surveys of primary care team clinicians (2012 and 2016) on barriers to palliative care, educational needs and awareness of palliative care support options were compared (chi-square, Mann-Whitney U tests, qualitative analysis). Palliative care referral characteristics were evaluated [2012–2017], including referral timing (survival since referral) (descriptive statistics, Kaplan-Meier methodology). Predictions of survival at referral were analyzed (weighted Kappa).

Results: In 2012 and 2016, the most frequently reported barrier was the late initiation of the palliative care approach. Clinicians reported a need for education on physical symptom management and basic palliative care principles. Awareness of support options increased from 2012 to 2016, including improved familiarity with the PCCT (56% *vs.* 85%, $P<0.001$) and positive appraisal of the team (8% *vs.* 40% gave an 'excellent' rating, $P<0.001$). The use of national symptom management guidelines also improved (23% *vs.* 53%, $P<0.001$). Of 1,404 referrals, 86% were for cancer patients. Referrals increased by 28% (mean) per year. Medical oncology clinicians referred most frequently (27%) and increasingly early in the disease trajectory (survival ≥3 months after referral) ($P=0.016$). Median survival after referral was 0.9 (range, 0–83.3) months. Referring physicians overestimated survival in 44% of patients (kappa 0.36, 95% CI: 0.30–0.42).

Conclusions: Primary care team clinicians persistently reported needing support with basic palliative care skills. PCCTs should continuously focus on educating primary care teams and promoting the use of guidelines. Because physicians tend to overestimate survival and usually referred patients late for specialist palliative care, consultation teams should support primary care teams to identify, treat and refer patients with palliative care needs in a timely manner.

Keywords: Specialist palliative care; hospital; referral; consultation

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Introduction

Within the generalist-plus-specialist palliative care model (1-3), all clinicians (both nurses and physicians) are expected to provide primary palliative care for patients with advanced illnesses, consisting of managing physical and psychological problems and having conversations about prognosis, treatment goals and life-sustaining treatments (2,3). However, in daily practice, hospital primary care clinicians often received limited education on palliative care and therefore focus mainly on treating the disease (4-8). This may prevent them from adequately caring for their patients, including not recognizing when to integrate a palliative care approach alongside disease-directed treatments and when to involve palliative care specialists (9). Hospital-based palliative care consultation teams (PCCTs) are increasingly available to support primary care teams and to provide specialist palliative care for patients with complex needs, such as refractory symptoms or difficult psychosocial and existential problems. To optimize hospital-based palliative care it is important that PCCTs not only invest in clinical care but also in nonclinical activities to improve the care provided by primary care teams (1,10). When our PCCT started in 2012, efforts were made to design a comprehensive nonclinical strategy. Core components were educational activities in each hospital department, marketing the added value of the PCCT and implementing palliative care support options for primary care teams. These support options included developing hospital-wide palliative care guidelines, promoting existing national symptom management guidelines and introducing the Surprise Question (11). Our PCCT specialists also trained primary care team clinicians to act as 'palliative care champions' (12,13). These champions were educated on diverse palliative care subjects four times per year (during 1.5-hour meetings) and served as palliative care ambassadors within their own hospital department, disseminating knowledge when needed.

Until now, studies have focused on identifying factors that facilitate or hinder palliative care referral (9) and collaboration between primary care teams and PCCTs within clinical patient care (14). None have evaluated how PCCTs can best support clinicians within their hospital to improve their primary palliative care skills. Our study aimed to assess the self-perceived barriers and educational needs of our hospital's primary care team clinicians in order to tailor our nonclinical activities to meet their support needs. In addition, we assessed their awareness of available palliative care support options and evaluated referral patterns.

We present this study in accordance with the Strengthening the Reporting of Observational studies in Epidemiology (STROBE) reporting checklist (available at http://dx.doi.org/10.21037/apm-20-1706).

Methods

Context

The Leiden University Medical Center had 25.634 hospital admissions per year in 2017 and a mean of 504 in-hospital deaths per year between 2014 and 2016. The PCCT was initiated in 2012 and consists of nurses, nurse practitioners and physicians specialized in palliative care. Inpatients and outpatients can be referred by physicians and nurses of primary care teams, and by self-referral of patients and their family members. All referred patients are discussed in weekly multidisciplinary team meetings involving PCCT consultants, clinicians from the patient's primary care team, social workers, liaison nurses, medical psychologists, pharmacologists, spiritual counsellors, medical oncologists, radiation oncologists and pain specialists.

Data collection

Part A: baseline and follow-up survey on barriers, educational needs and awareness of palliative care support options

Shortly after the start of the PCCT in 2012, a survey was sent by email to all medical and nursing managers of the 26 hospital departments providing patient care. The managers were asked to request a number of nurses and physicians to fill out the survey, serving as department representatives (baseline). In 2016, the survey was sent again (follow-up), with the same request. Surveys were filled out anonymously. The survey was developed by the PCCT consultants who based the content on their experiences with supporting primary care clinicians. Face validity and clarity of questions were assessed by a pilot sample of primary care team hospital nurses and physicians and questions were adjusted according to their feedback. The survey consisted of eight open-ended and 26 multiple-choice questions. An English translation of the full survey is provided in Appendix 1.

In this study we report the outcomes of two open-ended survey questions on self-perceived barriers to palliative care and educational needs: question 1 "which barriers do you experience regarding the treatment and support of patients with palliative care needs?" and question 2 "on which topic(s) regarding palliative care would you like education or training?". We also report the outcomes of six multiple-choice questions on awareness and use of palliative care support options, such as the PCCT, national palliative care symptom management guidelines, and departmental palliative care champions.

Part B: cohort study

Data on all patients referred to the PCCT from January 2012 to December 2017 were retrospectively collected from the electronic patient files. One physician (LS) and one nurse practitioner (EN) collected the following data: age, sex, primary diagnosis, referring department, referral date, inpatient or outpatient referral, date of death or last contact and disease phase (disease-directed or symptom-directed at time of referral; registered by a PCCT consultant from June 2014 onwards). Primary diagnosis was categorized into cancer, dementia/frailty, neurological disease, heart/vascular disease, respiratory disease, kidney disease, liver disease and other (15). Survival data were updated until February 6, 2020. Observed survival (OS) was defined from referral until death or last contact. To evaluate timing of referral, OS of referred patients was calculated in those departments that referred at least 10% of referrals from 2012 to 2017. We characterized early palliative care (OS ≥3 months), late palliative care (OS ≥2 weeks to <3 months) and care in the dying phase (OS <2 weeks) to evaluate yearly changes in the timing of referrals.

Part C: clinical prediction of survival at referral

From June 2014 onwards, all physicians were asked at referral if they would be surprised if their patient would die within 1 year, 3 months or 2 weeks to assess their ability to prognosticate.

The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study protocol was approved by the institutional ethics board of Leiden University Medical Center (G19.050) and individual consent for this retrospective analysis was waived.

Statistical analysis

Part A: baseline and follow-up survey on barriers, educational needs and awareness of palliative care support options

Answers to the open-ended questions were analyzed qualitatively to identify the topics within respondents' answers. The frequency of identified topics was then analyzed using descriptive statistics. Coding was done independently by a physician (LS) and nurse practitioner (EN) using pre-established codes, based on the Netherlands Quality Framework for Palliative Care (16) (see *Table 1*). If the answers did not fit the pre-established codes, inductive coding was done using thematic analysis (17). Disagreements were solved by discussion. The final set of codes was shared with other research team members for consensus, to obtain a definitive set of identified topics. Differences between the 2012 and 2016 outcomes of multiple-choice questions were analyzed using either chi-squared (dichotomous variables) or Mann-Whitney U tests (ordinal variables). Differences were considered statistically significant if P values were <0.05.

Part B: cohort study

Referral characteristics were analyzed descriptively. OS was calculated using the Kaplan-Meier method. Yearly changes in referral timing in frequently referring departments were evaluated using the Kruskal-Wallis test.

Part C: clinical prediction of survival at referral

OS and predicted survival were compared using weighted Kappa (18).

Results

Part A: baseline and follow-up survey on barriers, educational needs and awareness of palliative care support options

Respondent characteristics

In 2012, 291 primary care team clinicians filled out the survey, representing 92% of hospital departments (24/26 departments). In 2016, 195 clinicians filled out

Table 1 Frequency of identified topics within answers to two open-ended survey questions on self-perceived barriers to palliative care and educational needs (2012 and 2016)

Topic	2012 resp.[a]		2016 resp.[a]		Illustrative quotes
	n[b]	[%][b]	n[b]	[%][b]	
Question 1: which barriers do you experience regarding the treatment and support of patients with palliative care needs?					
Total respondents question 1	134		110		
Late initiation of palliative care[c]	33	[25]	22	[20]	“Disease treatment is continued too often when tender, love and care would be more appropriate” (pulmonology nurse, 2012); “Stopping curation and starting palliation is initiated too late” (general surgery physician, 2016)
Logistical issues	26	[19]	8	[7]	“Practical issues, like not having the possibility to let the patient rest in a soft chair or on a bed” (clinical geriatrics nurse, 2012); “A lack of time to offer adequate support and education of patients” (neurology physician, 2016)
Problems regarding joint decision-making[c]	8	[6]	9	[8]	“Problems with guiding patients in their choice for dialysis or for a palliative care trajectory” (nephrology nurse, 2012); “More discussions with patients and their family regarding if the patient wants to keep on living with endless treatments” (general surgery nurse, 2016)
Issues in communication with patients	7	[5]	3	[3]	“Patients and family are insufficiently informed” (gastroenterology/pulmonology nurse, 2012); “Especially difficulties in communication regarding prognosis and acceptance” (internal medicine physician, 2016)
Lack of proactive care planning[c]	13	[10]	9	[8]	“Patients will arrive at the emergency department, with whom it has never been discussed what the patient would want if they would ever be in a resuscitation setting or something similar” (ED[d] nurse, 2012); “Refraining from life-sustaining treatments is discussed too late” (medical oncology nurse, 2016)
Inadequate interdisciplinary collaboration[c]	19	[14]	7	[6]	“Gaps in collaboration of the treatment team due to insufficient communication” (pediatrics nurse, 2012); “Difficult to get into contact with other involved healthcare professionals on short notice” (medical oncology nurse, 2016)
Lack of attention for informal care givers[c]	5	[4]	3	[3]	“No guidelines available for [...] family members” (hematology nurse, 2012); “Family is not supported in a timely manner, especially regarding acceptance” (pulmonology physician 2016)
Insufficient coordination and continuity of care[c]	15	[11]	9	[8]	“Lack of a coordinator who coordinates care in both the outpatient department and at home” (medical oncology nurse, 2012); “Treatment decisions that were made together with the patient elsewhere are unknown in the hospital” (ED[d] nurse, 2012)
Lack of knowledge and expertise[c]	15	[11]	15	[14]	“Little palliative care knowledge, for example regarding educating patients about symptom management and supporting patients and their families” (pulmonology nurse, 2012); “Little experience, thus little knowledge” (general surgery nurse, 2016)
Lack of guidelines use[c]	–	[–]	1	[1]	“Palliative care protocol is not used” (cardiology nurse, 2016)

Table 1 (*continued*)

Table 1 (*continued*)

Topic	2012 resp.^{a}		2016 resp.^{a}		Illustrative quotes
	n^b	[%]^b	n^b	[%]^b	
Issues with management of physical symptoms^c	13	[10]	13	[12]	"Issues with treating pain in the right way and with treating delirium" (neurology nurse, 2012); "In my opinion, it sometimes takes too long time before patients are comfortable (regarding pain, dyspnea and restlessness)" (internal medicine nurse, 2016)
Inadequate management of psychological symptoms^c	8	[6]	5	[5]	"Dealing with coping and mood" (psychiatry nurse, 2012); "Lack of psychological support in palliative care trajectories" (internal medicine physician, 2016)
Social problems^c	4	[3]	–	[–]	"The high psychological burdening of the family" (internal medicine nurse, 2012); "Burdening of proxies" (general surgery nurse, 2012)
Issues with management of spiritual problems^c	–	[–]	1	[1]	"A this moment, there is a patient with an anthroposophical philosophy of life, which is not in line with the hospital's philosophy. Support is therefore difficult" (medical oncology nurse, 2012)
Inadequate terminal care^c	3	[2]	2	[2]	"Physicians are very rigid regarding initiation of palliative sedation. When sedation is initiated, we nurses have to fight for them to get morphine and/or midazolam" (neurology nurse 2012); "That midazolam is often not administered, or too late, while it would be appropriate" (neurology nurse 2012)
Lack of attention for loss and grief^c	1	[1]	4	[4]	"Because we reside in a medical environment, the approach is often also very medical and therefore, other aspects of saying goodbye to life and moving towards death are threatened to be overlooked" (medical oncology nurse, 2012)
Burdening of clinician	3	[2]	5	[5]	"Conversations in the middle of your daily schedule can be emotionally burdening for yourself as care provider" (ENT^e physician, 2012); "Sometimes my own sense of powerlessness" (gynecology nurse, 2016)
Problems with PCCT consultation	–	[–]	12	[11]	"Resistance among residents to refer to the PCCT early" (clinical geriatrics nurse, 2016); "Sometimes the PCCT is consulted too late, physicians do not always find it necessary" (gynecology nurse, 2016)
Inadequate medication administration skills	6	[4]	4	[4]	"Pain medication and sedatives are initiated too late and there are difficulties with finding the right dosage" (intensive care nurse, 2012); "Supporting and initiating the right medication" (neurology physician, 2016)
Question 2: on which topic(s) regarding palliative care would you like education or training?					
Total respondents question 2	61		72		
Initiation of palliative care^c	1	[2]	–	[–]	"When to stop/not to start treatment" (ENT^e physician, 2012)
Communication with patients	9	[15]	8	[11]	"Conversation techniques" (hematology/medical oncology nurse, 2012) ; "In particular, how to talk to patients with palliative care needs" (radiation oncology physician, 2016)

Table 1 (*continued*)

Table 1 (*continued*)

Topic	2012 resp.[a]		2016 resp.[a]		Illustrative quotes
	n[b]	[%][b]	n[b]	[%][b]	
Proactive care planning[c]	4	[7]	8	[11]	“Discussing life-sustaining treatment limitations” (radiation oncology physician, 2012); “Life-sustaining treatments and the talk about the end of life…‘Where would you like to die? How can we arrange that, if possible?’” (anesthesiology physician, 2016)
Interdisciplinary collaboration[c]	4	[7]	1	[1]	“How to deal with different opinions within the treatment team” (hematology/internal medicine/medical oncology nurse, 2012); “How responsibilities are divided between nurses and physicians when performing palliative sedation” (pediatrics nurse, 2012)
Coordination and continuity of care[c]	3	[5]	2	[3]	“Collaborative care in a palliative care trajectory” (medical oncology nurse, 2012); “How to arrange terminal home care” (general surgery nurse, 2016)
Guidelines[c]	2	[3]	1	[1]	“Guidelines” (urology physician, 2012); “Palliative care protocols” (neurology nurse, 2016)
Management of physical symptoms[c]	18	[30]	15	[21]	“Pain management, how to keep the patient comfortable, also in case of complications like pressure ulcers, new insights therein and treatment options” (general surgery nurse, 2012); “Palliative treatment of ileus” (internal medicine physician, 2016)
Management of psychological symptoms[c]	1	[2]	–	[–]	“Anxiety and depression in patients with palliative care needs” (anesthesiology physician, 2012)
Terminal care[c]	8	[13]	13	[18]	“Palliative sedation and euthanasia: what’s the difference?” (gastroenterology nurse, 2012); “The dying phase” (gastroenterology/pulmonology nurse, 2016)
Ethical and legal issues[c]	4	[7]	2	[3]	“Legal aspects of administering palliative sedation” (hematology nurse, 2012); “How to deal with life-sustaining treatment limitations, euthanasia, sedation. The ethical/moral aspects” (medical oncology nurse, 2016)
Consultation of the PCCT	8	[13]	4	[6]	“When to refer to the PCCT” (general surgery nurse, 2012); “Education on what the PCCT does exactly” (medical oncology nurse, 2016)
Medication	–	[–]	8	[11]	“Interaction of medication, discontinuation of medication (what is still useful?)” (internal medicine physician, 2016); “More information about morphine; dosage and application possibilities” (neurology physician, 2016)
Basic palliative care principles	12	[20]	14	[19]	“What is palliative care? (the basics)” (general surgery nurse, 2012); “All aspects of palliative care” (general surgery nurse, 2016)
No educational needs	3	[5]	4	[6]	“At this moment, none” (gynecology physician, 2012); “I already received training; it was complete” (orthopedics nurse, 2016)

[a], Respondents; [b], total n and percentage exceeds total n of respondents and 100% because free text answers provided by individual respondents could concern more than one topic; [c], domain of the Netherlands Quality Framework for Palliative Care (16); [d], emergency department; [e], ear, nose and throat surgery. PCCT, palliative care consultation team.

the survey, representing 96% of hospital departments (25/26 departments) (Table S1).

Open-ended question 1 on self-perceived barriers to palliative care

In 2012, 134 survey respondents (46%) and in 2016, 110 respondents (56%) reported on their self-perceived barriers to caring for patients with palliative care needs. All reported topics with illustrative quotes are listed in *Table 1*. In both years, the topic most often identified was the late initiation of palliative care (25% in 2012 and 20% in 2016). Respondents' main concerns were that disease-directed treatment is often continued too long. They also mentioned that patients who might benefit from palliative care are often identified too late. It was noted that physicians place too much focus on disease treatment which means that underlying problems that patients have are often not acknowledged.

In 2012, the second most identified topic was logistical issues, reported by 19% of respondents. Especially mentioned was a lack of time to adequately care for patients with palliative care needs. Respondents also reported insufficient resources, for example not being able to admit patients with complex needs because of bed shortages or not being able to offer patients' family members a bed to stay the night. In the outpatient clinic, a lack of comfortable chairs or beds to enable outpatients with palliative care needs to rest was mentioned. In 2016, the second most identified topic was insufficient general palliative care knowledge, reported by 14% of respondents, such as knowledge on pain management and when to refrain from life-prolonging treatments.

Open-ended question 2 on self-perceived educational needs

In 2012, 61 survey respondents (21%) and in 2016, 72 respondents (37%) reported on their self-perceived educational needs. All reported topics with illustrative quotes are listed in *Table 1*. In both years, most often mentioned were educational needs on the management of physical symptoms (30% in 2012; 21% in 2016). Clinicians commented on pain management and management of specific non-pain symptoms, like dyspnea, ileus, nausea, anorexia and restlessness. In both years, respondents also often wanted to be educated on basic palliative principles (20% in 2012; 19% in 2016).

Multiple choice questions on awareness of palliative care support options

Familiarity with the PCCT increased from 56% in 2012 to 85% in 2016 (P<0.001) (*Table 2*). In 2012, 18% of the respondents consulted the PCCT frequently and this increased to 35% in 2016. Likewise, the number of respondents who rarely or never consulted the PCCT decreased from 56% in 2012 to 32% in 2016 (P<0.001). In 2012, 8% of respondents appraised their experiences with the PCCT as excellent and 71% as good, and this increased to 40% and 49% of respondents in 2016 (P<0.001). Use of national palliative care symptom management guidelines among physicians increased from 37% to 87% (P<0.001). In 2016, 49% of respondents were aware of the presence of a palliative care champion nurse and/or physician within their own department.

Part B: cohort study

Palliative care referral characteristics

From 2012 to 2017, clinicians referred 1,404 patients to the PCCT. Referral, patient and follow-up characteristics are summarized in *Table 3*. Eighty-six percent of referred patients were primarily diagnosed with cancer, 43% were younger than 65 years and 23% were outpatients. Referrals increased by a mean of 28% per year (*Figure 1*). The proportion of referrals for non-cancer patients compared to overall referrals per year increased by a mean of 2.7% per year; 14% of referrals were non-cancer patients in 2012 and 18% in 2017.

Patients were referred most frequently by clinicians working in medical oncology, radiation oncology, pulmonology, and general surgery (see Figure S1 for referrals per hospital department per year).

Timing of referral

At study closure, 98% of referred patients had died (n=1,373). The median OS since referral was 0.9 (range, 0–83.3) months. When looking at timing of referral, clinicians referred 26% of patients early (OS after referral ≥3 months), 37% late (OS after referral ≥2 weeks and <3 months) and 37% in the dying phase (OS after referral <2 weeks) (*Table 3*).

Median survival differed between the four main referring departments (medical oncology: median 1.5 months, range 0–54.0 months; radiation oncology: median 3.2 months, range 0–83.3 months; pulmonology: median 0.7 months, range 0–38.0 months; and general surgery: median 0.5 months, range 0–37.9 months). The proportion of early palliative care referrals (OS after referral ≥3 months) increased over time only in referrals

Table 2 Outcomes of multiple-choice questions of baseline and follow-up surveys on palliative care support options

Survey questions and response options	2012, n [%]			2016, n [%]			P value[a]
	All (n=291)	Physician (n=52)	Nurse (n=239)	All (n=195)	Physician (n=61)	Nurse (n=134)	
Do you know the PCCT?							<0.001
Yes	79 [56]	21 [70]	57 [52]	165 [85]	57 [93]	108 [81]	
No	61 [44]	9 [30]	53 [48]	30 [15]	4 [7]	26 [19]	
How often do you make use of the PCCT?							<0.001
Frequently/often	14 [18]	6 [28]	8 [14]	58 [35]	20 [35]	38 [35]	
Sometimes	20 [26]	5 [24]	15 [26]	54 [33]	22 [39]	32 [30]	
Rarely/never	44 [56]	10 [48]	34 [60]	53 [32]	15 [26]	38 [35]	
What is your experience with the PCCT?							<0.001
Fair	0 [0]	0 [0]	0 [0]	4 [2]	0 [0]	4 [4]	
Reasonable	10 [21]	4 [23]	6 [19]	15 [9]	8 [14]	7 [6]	
Good	34 [71]	11 [65]	23 [74]	80 [49]	25 [44]	55 [51]	
Excellent	4 [8]	2 [12]	2 [7]	66 [40]	24 [42]	42 [39]	
Do you use the national palliative care symptom management guidelines?							<0.001
Yes	32 [23]	11 [37]	21 [19]	103 [53]	53 [87]	53 [40]	
No	108 [77]	19 [63]	89 [81]	92 [47]	8 [13]	81 [60]	
Task force[b] for patients with palliative care needs within your department?							0.23
Yes	25 [20]	11 [38]	14 [14]	50 [26]	25 [41]	25 [19]	
No	101 [80]	18 [62]	83 [86]	145 [74]	36 [59]	109 [81]	

[a], differences between answers of all respondents (physicians and nurses) in 2012 and 2016; statistically significant at <0.05; [b], groups of clinicians within hospital departments who aim to develop policy for patients with palliative care needs (for example, a pain management taskforce for patients with advanced illnesses within the anesthesiology department). PCCT, palliative care consultation team.

made by medical oncology clinicians (P=0.016) (*Figure 2*).

Part C: clinical prediction of survival at referral

Referring physicians predicted survival in 434 patients. Survival was correctly predicted in 50% of patients and overestimated in 44% (kappa 0.36, 95% CI: 0.30–0.42) (*Table 4*). Survival predictions were least accurate in patients with an OS of less than 2 weeks.

Discussion

In our study, self-perceived barriers to palliative care among primary care team clinicians were the late initiation of a palliative care approach and a lack of palliative care knowledge within their own team. Respondents reported the need for education mainly in physical symptom management and basic palliative care principles. Both barriers and educational needs were largely similar in the two surveys with 5 years in between despite increased awareness and use of palliative support options and a steady yearly increase of PCCT referrals. This may be due to the high turnover of junior clinicians working in our teaching hospital. In addition, clinicians may not be able to develop routine or build confidence in providing palliative care because they care for patients with advanced illnesses too infrequently. Barriers and educational needs also persisted despite PCCT efforts to target these topics through their nonclinical activities from

Table 3 Palliative care referrals: patient, referral and follow-up characteristics (2012–2017)

Variables	Cohort (n=1,404)	
	N/median	[%/range]
Age at time of consultation, years, median [range]	67	[17–98]
Age category, n [%]		
<45 years	113	[8]
45–65 years	484	[35]
65–75 years	467	[33]
75–85 years	244	[17]
>85 years	96	[7]
Female sex, n [%]	701	[50]
Primary diagnosis, n [%]		
Cancer	1,203	[86]
Non-cancer	201	[14]
Dementia/frailty	33	[2]
Neurological disease[a]	53	[4]
Heart/vascular disease[b]	53	[4]
Respiratory disease[c]	22	[2]
Kidney disease[d]	14	[1]
Liver disease[e]	4	[0]
Other non-cancer conditions[f]	22	[2]
Disease phase[g], n [%]		
Disease-directed treatment	190	[32]
Symptom-directed treatment	395	[68]
Site of consultation, n [%]		
Clinical ward	1,015	[72]
Outpatient clinic	323	[23]
Other[h]	66	[5]
Survival in months, median [range]	0.9	[0–83.3]
Timing of palliative care referral, OS [%]		
Early referral (survival ≥3 months)	359	[26]
Late referral (survival ≥2 weeks and <3 months)	526	[37]
Dying phase referral (survival <2 weeks)	519	[37]

[a], hemorrhagic or ischemic stroke, degenerative neurological diseases, myasthenia gravis; [b], heart failure, peripheral arterial disease, vascular or cardiac infections; [c], chronic obstructive pulmonary disease, sarcoidosis, pneumothorax; [d], renal failure due to vasculitis, nephrosclerosis, contracted kidney; [e], liver failure due to cirrhosis; [f], diabetes, infections, auto-immune diseases, trauma; [g], disease phase was classified by a PCCT consultant, from June 2014 onwards resulting in n=819/1,404 (58%) missings; [h], contact by telephone with general practitioner or home care. PCCT, palliative care consultation team; OS, observed survival.

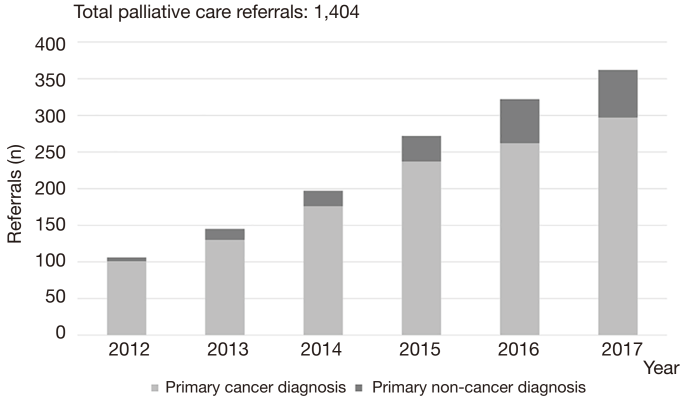

Figure 1 PCCT referrals 2012–2017. PCCT, palliative care consultation team.

2012 onwards. An overview of all our nonclinical activities is provided in *Table 5*. We based these activities on the 2012 and 2016 survey outcomes and added information from the literature on barriers for PCCT integration (1,10,14,19,49), and on changing clinical behavior (20,30).

The identified self-perceived barriers and educational needs are in line with reported topics identified in interview studies among hospital primary care team physicians and nurses (50,51). Although late initiation of palliative care was the most reported barrier in our surveys, only one clinician in 2012 mentioned this as an educational need. This suggests a lack of awareness among clinicians that knowing when to initiate a palliative care approach is a distinctive skill that can be improved through education and support. Moreover, the survey answers reported by respondents regarding the initiation of palliative care suggest that primary care team clinicians are insufficiently aware of integrated palliative care, where palliative care is provided alongside disease-directed treatment (52,53). The traditional approach of starting palliative care only after all disease-directed treatment is complete has been identified as a barrier to initiating palliative care in a timely manner (4) and to collaborating with a PCCT (14,54). Our PCCT focused on teaching primary care clinicians how to identify patients who might benefit from palliative care. For example, to increase their awareness, from 2014 onwards, upon each referral request the referring physician is asked to answer the 1 year, 3 months and 2-week Surprise Question (11). To improve symptom management, the PCCT introduced the Dutch version of the Edmonton Symptom Assessment System (ESAS) (33,55).

Combining referral patterns with the survey outcomes provides directions for how to improve hospital-based palliative care. Evaluation of our referral characteristics confirmed that clinicians tend to seek less PCCT support for non-cancer patients than they do for cancer patients (21,36-41). It is easier to identify palliative care needs in cancer patients because they usually have steady disease progression with a distinct terminal phase. In contrast, patients with organ failure usually decline gradually with acute exacerbations that may or may not lead to death, and death is often seemingly unexpected (53,56-58). Positively, a small increase in referral of non-cancer patients was observed over the years in our hospital, which is in line with a recent evaluation of 88 US PCCTs (39).

Difficulties initiating palliative care are probably related to the overestimation of survival, both in this study and previous evaluations (59-61). In our study, referrers were more likely to overestimate the survival of patients who survived less than 2 weeks after referral. Only a quarter of patients were referred ≥3 months before death. After referral, our patients lived a median of 27 days, which is comparable with other reports (range, 12–44 days) (37,38,40,42-44). Initiating palliative care early (expected survival ≥3 months) is important, since it improves quality of life and survival and reduces in-hospital deaths, emergency room visits, and hospitalizations in the last phase of life (62,63). Positively, our medical oncology clinicians referred an increasing proportion of their patients for early palliative care (OS ≥3 months) over time. This learning curve regarding the timing of referral was only observed in this department, which may be explained by the intensive collaboration between the PCCT and medical oncology

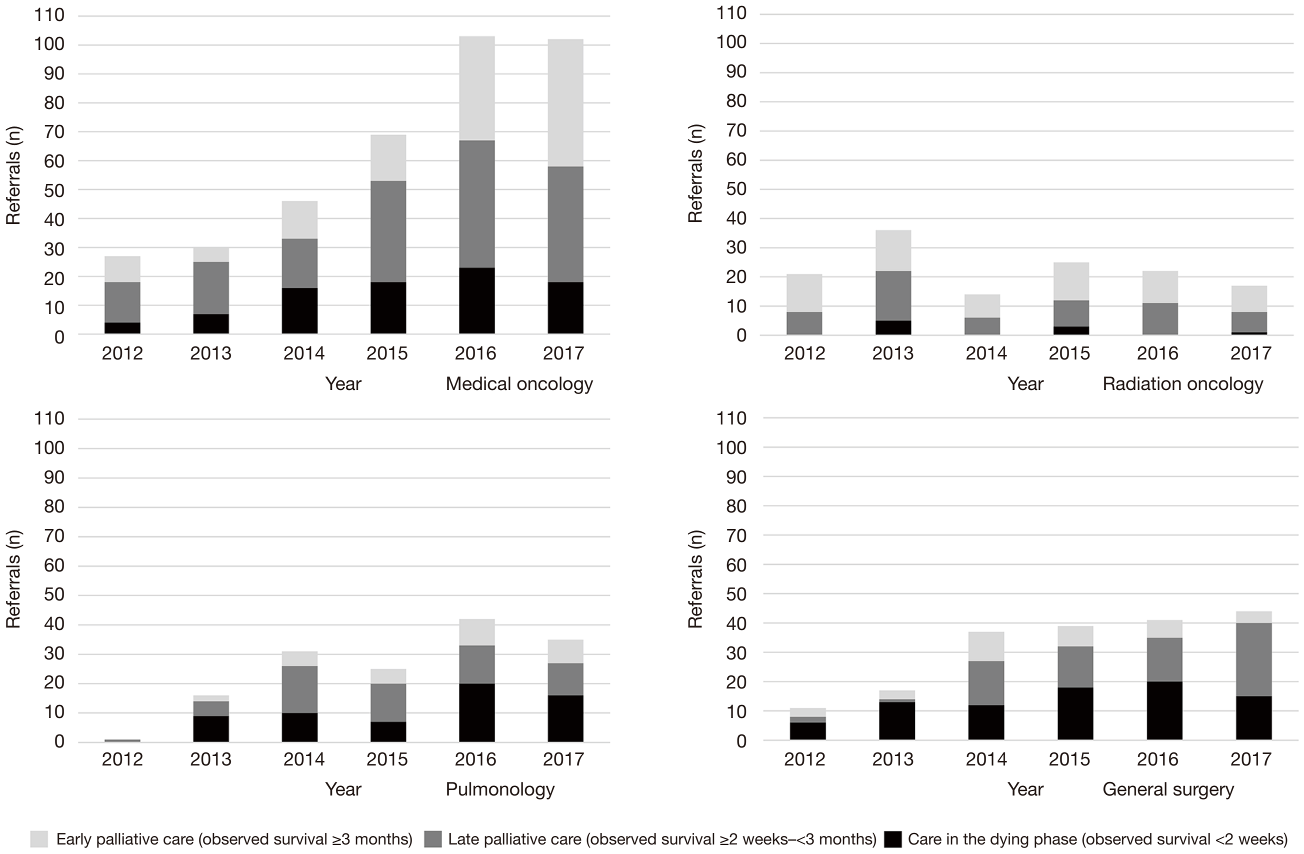

Figure 2 Timing of referrals to the PCCT for departments that referred >10% of all patients between 2012 and 2017. PCCT, palliative care consultation team.

Table 4 Clinical prediction of survival by referring physician compared to OS

Predicted survival	OS, n [%[a]]		
	<2 weeks[b] (n=200)	≥2 weeks to <3 months[c] (n=158)	≥3 months[d] (n=76)
<2 weeks (n=77)	70 [35]*	6 [4]	1 [1]
≥2 weeks to <3 months (n=223)	112 [56]	91 [57]*	20 [26]
≥3 months (n=134)	18 [9]	61 [39]	55 [73]*

*, correct prediction; [a], percentage of patients compared with total patients (n) within OS category; [b], survival <2 weeks: care in the dying phase; [c], survival ≥2 weeks to <3 months: late palliative care; [d], survival ≥3 months: early palliative care. OS, observed survival.

clinicians, alongside ample attention in their field for integrated palliative care in general (22,28,49). Additional nonclinical activities to improve PCCT referrals and timing thereof are presented as suggestions in *Table 5*. The overview of nonclinical activities in *Table 5* may help other PCCTs to plan and improve their nonclinical strategies.

Strengths and limitations

Our study combines data on self-perceived palliative care barriers and educational needs of clinicians and referral patterns. This information has allowed us to suggest ways to explain referral patterns and to improve hospital-

Table 5 Nonclinical activities of the Leiden University Medical Center PCCT supporting implementation of integrated palliative care

Prerequisites	Barriers[a]	Examples of nonclinical PCCT activities
Set-up		
Support of hospital management and senior clinicians (10,19)	● Changing clinical behavior is complicated if management or opinion leaders are not interested or disagree with the aspired change (20) ● Due to the interdisciplinary nature of palliative care, a lack of ownership is a specific problem (21)	● Have regular meetings with hospital management and heads of departments
Funding (19)	● There is a lack of adequate reimbursement for palliative care services (4)	● Hold regular budget negotiations on revenues and costs, with hospital financial department and insurance companies
Estimation of staffing needs (1)	● It is difficult to estimate needs in advance, due to a lack of historical framing of PCCT staffing and the lack of insight in expected increase in consultations (1)	● Review the PCCT's time investment in (non)clinical activities to determine staffing needs. Use national and international benchmarks (1,10,21)
Considering with which disciplines to staff the team (1,22)	● Primary care team clinicians are less likely to refer to homogenous teams compared to monodisciplinary teams (14) ● Limited multidisciplinary palliative care is less effective than comprehensive multidisciplinary care (22)	● Core disciplines: palliative care nurses and physicians ● Intensive collaboration with other disciplines: social workers psychologists, spiritual care givers, volunteers, pharmacists, pain specialist, medical oncologists
Referral process		
Establishing which patients can be referred	● Relatively few early referrals are for inpatients compared to outpatients (23) ● Many hospitals do not offer the possibility of outpatient palliative care consultations (21,23)	● Availability for inpatients and outpatients ● Encourage outpatients referrals ● Offer the opportunity for outpatient palliative care consultations by telephone. Try holding the outpatient PCCT appointment on the same day as an outpatient appointment with the medical specialist, to convenience the patient
Deciding on a referral model (19,22)	● Referrals are usually made by physicians. It depends on their knowledge and expertise whether a palliative care consultation is requested (9)	● Referrals can be made by all hospital clinicians: physicians, residents, nurses ● Self-referral by patients or relatives is possible ● Suggestion[c]: consider triggered referral, wherein an order for or consideration of PCCT referral is automatically initiated if pre-set criteria are met. However, no consensus on trigger criteria (24) ● Suggestion[c]: consider proactive case finding: screen for patients who may benefit from referral. Practiced in non-oncology departments in a hospital that reported 74% of referrals being made for non-cancer patients (25)

Table 5 (*continued*)

Table 5 (*continued*)

Prerequisites	Barriers[a]	Examples of nonclinical PCCT activities
Deciding on the availability of the team (10)	● Slow response and limited availability of the team impede the collaboration between the primary palliative care team clinicians and the PCCT (14)	● Availability during office hours ● Palliative care consultations during nights and weekends are handled by telephone by the regional PCCT
Formulate and disseminate clear referral criteria (1,26,27)	● It is difficult to identify patients who need palliative care referral (4) ● Clinicians disagree on when to refer a patient to the PCCT[b]	● Referral criteria formulated based on available literature (28,29) ● Digital dissemination and dissemination via pocket card
Marketing		
Promoting palliative care via awareness campaign (19)	● If clinicians are not aware of a problem or intervention, they will not change their clinical behavior (20,30)	● Intranet messages; palliative care surveys (see Appendix 1); organize palliative care symposiums
Marketing of the team (31)	● If clinicians are not convinced of the expertise of the PCCT members, they are less likely to refer (14) ● Clinicians are often unaware of the benefits of PCCT consultation and the ways in which PCCTs can support patient care	● Disseminate added value and goals of the team via patient folders and clinicians pocket card ● Suggestion[c]: consider a name change from the burdensome title 'palliative care team' to a less weighty 'supportive care team'. This has been shown to result in earlier timing of referrals for outpatients (32)
Education		
Continuous palliative care education (1)	● Clinicians report insufficient palliative care knowledge and a need for education on basic palliative care principles[b] ● Clinicians have unchanged palliative care educational needs after 5 years of PCCT activity[b] ● Most clinicians are insufficiently trained in or have limited experience with providing palliative care (10-14)	● Hospital-wide palliative care courses for physicians and nurses, aimed at specific barriers ● Structural education at clinical wards ● Educational sessions at request of departments ● Bedside teaching ● Mentorship of colleagues (1) ● Promote the integrated palliative care model
Support methods		
Training palliative care champions (12)	● Most clinicians are insufficiently trained or have limited experience with providing palliative care (10-14)	● Educate hospital nurses and physicians about diverse palliative care subjects four times per year (1.5-hour meetings), so they can serve as palliative care ambassadors within their department

Table 5 (*continued*)

Table 5 *(continued)*

Prerequisites	Barriers[a]	Examples of nonclinical PCCT activities
Stimulating palliative care guideline use	● At baseline in 2012, 77% of hospital clinicians did not use the national palliative care symptom management guidelines[b]	● Explicitly refer to national guidelines when giving recommendations to generalist clinicians during consultations ● Stimulate the development of palliative care protocols (1), for example department-specific guidelines
Introducing screening tools to identify patients with palliative care needs (1,19)	● Clinicians have difficulties with initiating palliative care[b]	● Introduce the Surprise Question (19)
Introducing multidimensional palliative care symptom assessment tools (19)	● Clinicians require support with symptom management[b] ● Clinicians underestimate symptom presence and intensity (34,35)	● Introduce the Utrecht Symptom Diary (Dutch translation and adaptation of the Edmonton Symptom Assessment Scale) (33)
Quality assessment		
Evaluation (19,20) of palliative care support awareness and support needs	● It is difficult to change clinical behavior and ultimately patient care, if bottlenecks within the specific hospital have not been identified (20,30)	● Baseline survey among hospital physicians and nurses (see Appendix 1) ● Compare outcomes of baseline and follow-up surveys
Evaluations of PCCT data (10)	● There is limited PCCT involvement for patients with a non-cancer primary diagnosis (21,36-41)[b]	● Assess for which patients the PCCT is consulted, in terms of primary diagnosis and from which hospital departments
	● Timing of referrals is usually late (37,38,40,42-44)	● Review timing of consultations for departments that account for more than 10% of referrals over several years, because a learning curve regarding timing of referral may be expected
Research		
Initiating and coordinating palliative care research (1,19)	● The evidence base in palliative care is limited (45)	● Develop, evaluate and implement a palliative care Question Prompt list (46)
	● Coordinating research is difficult due to the interdisciplinary nature of palliative care (45)	● Evaluate the quality of palliative care for cancer patients visiting the emergency department (47,48)

[a], Barriers: described in the literature on integration of palliative care/palliative care services, literature on changing clinical behavior in general or identified in this study; PCCT, palliative care consultation team; [b], identified in this study, through comparing baseline and follow-up survey results and evaluation of PCCT consultation data; [c], nonclinical activities suggested by others, but not implemented in our hospital.

based palliative care. Although this is a single-center study with a specific organization of palliative care, the identified barriers, educational needs and referral patterns are similar to those reported in previous studies. Thus, other PCCTs may find our outcomes helpful to further integrate palliative care into their hospitals. A limitation is that PCCT members analyzed the qualitative survey data on their own performance, which may be a source of bias. Furthermore, clinicians who filled out the surveys may have had a higher affinity to palliative care than non-responders, which may have affected the survey results (non-response bias). Registration bias may also be present because of the retrospective nature of the referral analysis.

Conclusions

Despite increased awareness and use of available palliative care support options, self-perceived barriers and educational needs of primary care team clinicians persisted after 5 years of clinical and nonclinical PCCT activities. Primary care teams usually referred late for specialist palliative care and tended to overestimate survival at referral.

Therefore, we recommend that PCCTs focus their nonclinical activities on improving general palliative care knowledge among primary care team clinicians. PCCTs should especially support hospital clinicians to identify patients who might benefit from palliative care in a timely manner.

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Footnote

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