ORIGINAL ARTICLE

MASCC/ESMO/EAPC survey of palliative programs

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Abstract

Background Palliative care program structure is important to integrating palliative services into cancer care. A first step in understanding the structure of palliative care programs is to survey existing programs.

Method This data was generated from members of MASCC, the European Society of Medical Oncology (ESMO), and the European Association of Palliative Care (EAPC) who completed the surveys on the website. A survey questionnaire was developed using the survey tool developed by Dr. Hui and colleagues by permission which was modified for the purposes of this study. Findings were described in number and percentages. Inferential statistics involved the Fisher's exact test for factors with two levels, chi-Square test for unordered categorical factors with greater than two levels, Cochran-Armitage trend test for ordered categorical factors, and the Wilcoxon rank sum test for measured factors.

Results Sixty-two program leaders completed the survey. Most programs had been in existence greater than 5 years and were led by oncology trained physicians who had an

additional specialty. Most programs had consultative services and outpatient clinics with fewer having inpatient beds and institutionally associated hospices. Most programs provided patient continuity. Patients were generally seen late in the course of illness with the average survival of 23 days when seen as inpatients and 40 days when seen as outpatients. Less than half had palliative care fellowship training programs. Most had research structures in place.

Discussion These findings differ from results reported in a previous survey which may reflect a European palliative care program structure. However, there were similarities which include a high inpatient palliative care unit mortality and short survival of patients seen as outpatients, indicating that referrals to palliative care occur late in the course of cancer.

Conclusions This study not only differs in some respects to a previous survey of palliative care programs but also confirms the late referral of patients to palliative care.

Keywords Palliative \cdot Inpatient \cdot Consultative \cdot Mortality \cdot Service

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Introduction

Integration of palliative care into cancer care is highly endorsed by the World Health Organization, the Institute of Medicine, the European Society of Medical Oncology, and the American Society of Clinical Oncology [1, 2]. Palliative Care has increasing relevance for the care of advanced cancer patients [3, 4]. By improving quality of life with aggressive symptom management, reducing the cost of care, and possibly improving survival, palliative care can no longer be confused with care at the end of life [5–7].

Elements of palliative care include standard definitions, component parts, models of care delivery, standardized assessment tools, educational programs, fellowship training, and



accreditation. Very little is known about the structure of palliative care programs internationally. In light of this, the Multinational Association of Supportive Care on Cancer (MASCC), the European Society of Medical Oncology (ESMO), and the European Association of Palliative Care (EAPC) surveyed palliative programs through each society's membership.

Methods

Research design

This study used an analysis from a cross-sectional survey conducted through the MASCC website using Survey Monkey (www.surveymonkey.com/). The survey was in two parts and involved palliative care program leaders (Fig. 1). The first part centered on palliative care integration into oncologic care and is reported separately. This project was reviewed by the Cleveland Clinic Institutional Review Board and was granted exemption from consent. The main method of this survey was

a questionnaire which was modified from the original questionnaire by Dr. Hui and colleagues [8].

Sample

This data was generated from members of MASCC, ESMO, and the EAPC, who completed the survey on the website. Members were informed of the survey and invited to complete the survey by entering the MASCC website. Repeated invitations were made until no further surveys were received. The survey was sent November 15, 2011, to 676 MASCC members and made available on the MASCC website for non-MASCC members. The survey was removed from the website April 20, 2012.

Questionnaire

For the purposes of this study, a survey questionnaire was designed using a modified version of the survey tool developed by Dr. Hui and colleagues with their permission [8]. Modifications involved a question about designated ESMO

Survey for Palliative Care Program Leaders

sitting. It should take no more than 15 minutes. When answering questions regarding numbers or percentages, please use approximations (i.e. we do not expect you to look up the information in detail). Thank you! I. Palliative Medicine Services A. Does your institution provide any palliative care services? ☐ Yes (please complete this section) ☐ No (please skip to Section V) B. What is the name of your palliative care program? (Check all that apply) □ Comprehensive cancer care Pain and symptom management Palliative care П Supportive care ☐ Other: C. How long approximately has your palliative care program been officially seeing patients? ☐ 1-2 years ☐ 3-5 years D. What are the specific kinds of palliative care services that are available? (Check all that apply) Palliative care consultation/mobile team service Palliative care/supportive care clinic Dedicated palliative care acute care beds Institution operated hospice E. What are the type(s) of services that your palliative care team offers? (Check all that apply) ☐ Assessment and management of psychiatric disorders Assistance in obtaining advance directives and Do Not Resuscitate (DNR) Assistance in resolving complicated ethical issues Assistance with referrals to hospice, home care, or other placements П Comprehensive care plan for those requiring comfort care Pain consultation Psychosocial support □ Symptom management F. Approximately, what proportion of patients seen by palliative care belong to the pediatric age group (<18 year old)?

26-50%

□ 51-75%

□ 76-100%

Thank you for participating in this survey. Please try to complete the following survey in one

Fig. 1 Palliative care leadership survey

□ 0%

□ 1-25%



I. Palliative Medicine Serv G. What is the professional apply)			iative care	program le	eader? (Ch	eck all that
□ Anesthesia □ Family medicine □ Internal medicine □ Medical Oncology	nily medicine					
H. Within your program, ple assigned to palliative care:	ase indicate	the appro x	cimate nur	mber of pai	d personne	l
Personnel	0	1-5	6-10	11-25	26-50	>50
Ward nurses (inpatient)						
Clinic nurses (outpatient)						
Personnel	0	1	2	-5	6-10	>10
Chaplains					0.10	
Dieticians						
Mid-level providers						
(advanced nurse						
practitioners or physician						
assistants)						
Palliative care physicians						
Rehab (PT/OT)						
Pharmacists						
Psychiatrists						
Psychologists						
Social workers						
Other						
I. Approximately , how man your palliative care program		quivalent (F	TE) physic	cian positio	ons are ava	ilable in
J. Approximately , how ma academic protected time?	ny physicians	s on your p	alliative ca	re team ha	ive at least	20%
K. Does your palliative care and taken boards)?	program req	uire physic	cians to be	certified (f	inished a fe	llowship
□ Yes □ N	0					
L. Does your palliative care nursing)?	program req	uire nurses	s to be cert	tified (taker	n boards in	palliative
□ Yes □ N	0					

Fig. 1 (continued)

centers. Exemption from written or verbal informed consent was obtained from the Institutional Review Board of the Cleveland Clinic. Palliative Care program leaders entered the MASCC website to complete the survey using Survey Monkey (www.surveymonkey.com/). The questionnaire queried palliative care program leaders on the name of the program, how long the program was in existence, and the type of services provided (Fig. 1). Leaders were asked if their care included pediatric patients. Questions involved professional backgrounds of the program leader, number of full-time equivalence, certification and patient continuity. In regards to inpatient palliative care, leaders were asked about inpatient palliative care beds, duration of stay in hospital, number of inpatient

discharges per month, median survival after admission, reasons for admission, number of family conferences, and advanced directives. Questions regarding consultative services involved the presence of a consultative service, availability, number of referrals per month, survival, and referral sources. Regarding outpatient care, leaders were asked about outpatient clinics, number of days per week a clinic is held, referrals per month, and survival. A number of other questions were asked about institution-operated hospices, education services, fellowship programs, mandatory palliative care rotations for oncology fellows and other trainees, grand rounds, length of training for fellows, accreditation requirements, research and palliative care funding. Responses are reported for all leaders combined and broken



I. Palliative Medicine Services (continued) M. On average, how long does your palliative care team follow patients in your institution (all inpatient and outpatient encounters)? \square 1-7 days \square >1-4 weeks \square >1-12 months \square >1-2 years \square >2 years ☐ Throughout the patient's illness II. Inpatient Palliative Care Units/Beds A. Does your palliative care program have any dedicated acute care beds in your institution (NON-HOSPICE)? ☐ Yes (please complete this section) □ No (please skip to Section III) B. Number of designated palliative care beds: C. Is there a physical unit designated as the palliative care unit (PCU) and primarily for palliative care inpatients? □ Yes D. How long has your inpatient palliative care service been in place? <6 months ☐ 6 months-11 months ☐ 1-2 years 3-5 vears E. Approximate number of inpatient palliative care discharges per month? F. Approximate median duration of inpatient palliative care stay (days)? _ G. Approximate median days from admission to death (if available)? H. Approximate inpatient palliative care mortality rate (i.e. [death] / [total admissions])? I. Please indicate the approximate percentages for each potential reason for admission. A. Because they are imminently dying? ___ B. For acute symptom management? ____ C. For psychosocial reasons? D. For respite? E. Due to other reason(s) not mentioned above? _____%

a. Explain other reason(s):

Fig. 1 (continued)

down by whether the program is relatively new (less than 5 years old) or mature (greater than 5 years old).

Statistics

Findings were described in number and percentages. Inferential statistics involved the Fisher's exact test for factors with two levels, chi-square test for unordered categorical factors with greater than two levels, Cochran-Armitage trend test for ordered categorical factors and the Wilcoxon rank sum test for measured factors. A p<0.05 was considered statistically significant.

Results

Sixty-two program leaders completed the survey (Table 1). One responder indicated that his or her institution did not provide palliative care services and was therefore excluded

from analysis. Program names were often described using a single phrase. Thirty-six percent (22/61) used a single descriptor "Palliative Care", 39 % were described in two or more phrases (Table 1). The majority of the palliative programs completing the survey were >5 years (43/61, 70 %), 3 (5 %) were <1 year, 4 (7 %) 1–2 years, and 11 (18 %) 3–5 years old. Forty-nine (80 %) of programs had mobile/consultative teams, 80 (82 %) has palliative care/supportive clinics, and 38 (62 %) has inpatient beds dedicated to palliative care. Only half (30 or 49 %) had all three services and only 25 % (15) had an institutionally operated hospice. There was a trend for older programs to have outpatient clinics (p=0.09). Types of services offered included assessment and management of psychiatric disorders, discussions regarding advanced directives, resulting ethical complex issues, assisting with hospice referral, developing comprehensive care plans, pain and symptom management, and psychosocial support. Most programs (59 %) offered seven to eight services. Approximately 1/3 of programs cared for pediatric patients. Approximately half



II. Inpatient Palliative Care Units/Beds (continued)

J. Please indicate the approximate percentages of referral sources to your palliative care service.						
A. Intensive care unit?%						
B. Other inpatient units?%						
C. Emergency room?%						
D. Outpatient clinics?%						
E. Other hospitals?%						
F. Hospice?%						
G. Other,%. Please specify,						
$\label{eq:K.Approximately} \textbf{K. Approximately, what proportion of patients receives} \ \underline{\text{regular psychosocial assessments}} \ \text{on each admission?}$						
□ 0% □ 1-25% □ 26-50% □ 51-75% □ 76-100%						
L. Approximately , what proportion of inpatients has family <u>conferences</u> during admissions?						
□ 0% □ 1-25% □ 26-50% □ 51-75% □ 76-100%						
M. Approximately, how often do <u>primary oncologists</u> attend these family conferences?						
□ 0% □ 1-25% □ 26-50% □ 51-75% □ 76-100%						
N. Approximately, what proportion of inpatients has $\underline{\text{Do-Not-Resuscitate}}$ orders?						
□ 0% □ 1-25% □ 26-50% □ 51-75% □ 76-99% □ 100%						
III. Consultation Service						
A. Does your palliative care program have a dedicated <u>consultation service</u> in your institution? ☐ Yes (please complete this section) ☐ No (please skip to Section IV)						
B. How often is it available? 24 hours/7 days per week 24 hours/weekdays only Other: Other:						
C. Approximately, how many referrals per month?						
D. Approximately , how many <u>days</u> from referral to death?						
Referral sources: (Check all that apply) □ Emergency Department □ Hematology □ Radiation Oncology □ Other:						

Fig. 1 (continued)

(48 %) had >5 inpatient nurses dedicated to palliative care; 10 % had >5 outpatient clinic nurses dedicated to palliative care.

Most palliative care program leaders who completed the survey were oncologists (74 %) though 69 % of respondents recorded more than one specialty. The majority of programs have a chaplain, dietitian, mid-level provider, rehabilitation personal, psychologist, and social worker dedicated to palliative care. Less than half (27 of 62 programs, 46 %) had a dedicated pharmacist. The median number of full-time equivalent physicians was 2 (range 0–15) with half (55 %) of programs providing physicians with 20 % academic protected time. Thirty-five (58 %) programs required physician

certification in palliative care or to complete a palliative care fellowship; 47 % (28 /62) of program required nurse certification in palliative care.

Most programs (75 %) provided continuity (followed patients for greater than 4 weeks or throughout the course of disease). Seventy-four percent (43) had dedicated acute care beds within a unit with the median number of 10 beds (range 0–43), median length of stay was 10 days (range 3–98), and median discharges per month was 24 (range 2–250). The primary reason for admission to the inpatient palliative unit was symptom management (60 %). Admission for reason of imminent death was 10 %. However, the median inpatient palliative care mortality rate was 40 % (range 2–99 %). The



IV. Palliative Care Outpatient Clinic A. Does your palliative care program see patients in the outpatient setting? (Check all that
apply) Yes, we have a dedicated palliative care outpatient clinic (please complete this section) Yes, we see patients in oncology clinics (please complete this section) No (please skip to Section V)
B. Approximately , how many <u>days</u> per week is it held?
C. Approximately, how many referrals per month?
D. Approximate number of days from referral to death (if available)?
E. Referral sources: (Check all that apply) Emergency Department Medical Oncology Surgery Hematology Radiation Oncology Other:
 V. Hospice A. Does your institution operate a hospice? □ Yes □ No If yes, please indicate the approximate average hospice daily census:
VI. Educational Services Targeting Palliative Care
A. Fellowship program for Palliative Medicine? \square Yes \square No
If yes, approximate number of <u>clinical</u> fellows per year:
If yes, approximate number of <u>research</u> fellows per year:
B. <u>Mandatory</u> palliative care rotations for
Medical oncology/hematology fellows $\ \square$ Yes $\ \square$ No $\ \square$ Not applicable
Radiation oncology fellows
Pediatric oncology fellows
Medical students ☐ Yes ☐ No ☐ Not applicable
Other residents or fellows: Yes No Not applicable
C. Training of $\underline{\text{mid-level providers}}$ in palliative care: \square Yes \square No
D. Dedicated <u>palliative care grand rounds</u> : ☐ Yes ☐ No
If yes, how many times per week: \Box 1 \Box 2 \Box 3 or more
E. Length of training for fellows for certification: 1 Year 2 Years 3 Years Other
F. Are there palliative board examinations? ☐ Yes ☐ No
G. Are there recognized accreditation requirements to be recognized as a specialist in

Fig. 1 (continued

median number of days from admission to death was 10.5 (range 3–55 days). Major sources of referral to the inpatient unit were transfers from non-ICU acute care beds (20 %), emergency departments (10 %), and outpatient clinics (20 %), and only 5 % coming from intensive care units. In half of programs more than 75 % of patients in the hospital on palliative units had psychosocial assessments during admission, had family conferences during the inpatient stay, and most had standing DNR orders. However, only 36 % of

programs had the oncologist attend >75 % of family meetings, while 45 % of programs (N=19) stated that the oncologist attended 15 % or fewer family conferences. Although palliative inpatient consultative services were uniformly provided, most (57 %) were not 24 h/7 days a week services. On average, services had 25 referrals per month (range 3–400), and most sources of referral were medical and radiation oncology and surgery. The median time from inpatient consultation to death was 23 days (range 7–97).



A. Is there a research prog		car	re?				
☐ Yes (please compl☐ No (End of surve)							
B. The research team cons Chaplains Pharmacists Rehab therapists (PT/OT)	□ D	ata hys lese	analysts sicians earch nurses		☐ Psycho☐ Social		
	industry						
VII. Research in Palliative Care (continued) D. Please indicate the types of palliative care studies conducted over the last year: (Check all that apply) □ Prospective randomized therapeutic trials □ Prospective randomized non-therapeutic trials □ Other prospective non-randomized studies □ Retrospective studies □ Case series/case reports □ Qualitative studies □ Others. Please specify,							
E. Please indicate the app department last year:	roximate numbe	er <u>o</u>	f abstracts pres	ente	d at meetings b	y your	
Oncology conferences	(e.g. ASCO) 1-2		3-5		6-10	□ >10	
Palliative care conferer □ 0 □	nces (e.g. AAHPN 1-2		3-5		6-10	□ >10	
Others	1-2		3-5		6-10	- >10	
F. Please indicate the appr year:	roximate <u>numbe</u>	r of	papers publishe	d by	your departmer	nt last	
Oncology journals (e.g. □ 0	JCO, JNCI) 1-2		3-5		6-10	- >10	
Palliative care journals ☐ 0 ☐	(e.g. J Pall Med) 1-2		3-5		6-10	□ >10	
General medical journa ☐ 0 ☐	als (e.g. NEJM, J 1-2		A) 3-5		6-10	□ >10	

Fig. 1 (continued)

Outpatient clinics were held a median of 5 days/week (range 0.5–7) and saw a median of 30 new referrals per month (range 3–250). Most referrals were from medical and radiation oncology. Approximately half (45 %) had dedicated palliative care outpatient clinics only, 19 % saw patients in oncology clinics only and an additional 19 % saw patients both in palliative care outpatient clinics and oncology clinics.

Approximately 1/3 of palliative care programs (37 %) had active fellowship training, half (52 %) had one to two clinical fellows per year and half (48 %) had more than two clinical fellows in their program. Length of training for fellows to be certified was less than 1 year for 67 % of programs. Half of programs (56 %) had one to two research fellows per year. Excluding programs without ties to cancer care, half (56 %, 27/48)) of programs provided palliative care rotations for



VII. Integration A. During what stage do you see cancer patients? During curative chemotherapy, radiation and radiation П During palliative chemotherapy, radiation and surgery Once anticancer therapy is finished When patients are actively dying (less than one month to survive) B. Do members of the palliative care department attend (nurses, physicians)? □ Oncology conferences П Oncology tumor boards Oncology administrative meetings Oncology outpatient or inpatient services C. Do members of the oncology department attend (nurses, physicians)? ☐ Palliative medicine lectures ☐ Palliative medicine administrative meetings D. Are there oncologists who attend (provide service either inpatient or outpatient) on palliative care services ☐ Yes П № E. Are there palliative specialists who attend on oncology services (either outpatient or inpatient?) ☐ Yes No F. Is there any integration of the palliative care program with other departments? □ Intensive Care Geriatrics Cardiology Neurology П Pulmonology

Thank you for your participation!

Fig. 1 (continued)

oncology fellows, 33 % (14/43) for radiation oncology fellows, 51 % (23/45) for other fellows/residents, 35 % (15/43) for medical students, 9 % (3/31) for pediatric oncology fellows, and 61 % (34/56) trained mid-level providers. Half of programs incorporated Grand Rounds at least once per week (68 %) or two to three times per week (32 %).

Pediatrics

Pain medicine

Rehabilitation Other

Comments:

Approximately 2/3 of programs (64 %) had research programs, usually consisting of a physician (100 %), data analyst (75 %), research nurse (72 %), and psychologist (56 %). Less than half of these programs (44 %) were fully staffed and almost (62 %) had outside funding, usually from private foundations and philanthropy. Most research programs conducted prospective trials (86 %); half were involved in retrospective studies, case reports/series, and qualitative studies. For the most part, research programs reported their findings in palliative care and oncology journals. Seventy percent of these had one publication in a palliative care journal over the last

year, 68 % had at least one publication in an oncology journal, and 49 % had at least one in a general medical journal.

The number of young palliative care programs was small so results need to be taken with caution when compared to more mature programs. More mature programs had shorter hospital stays (median of 9.5; range 3–96) versus younger programs (median 14.5; range 9–98; p=0.007). Mature programs had a greater number of referrals (median 30, range 3–400) versus younger programs (median 15; range 4–40; p=0.04). Mature programs provided palliative care rotations for non-oncology fellows and residents more frequently (60 vs. 20 %; p=0.04).

Discussion

A picture emerges from this survey which characterizes palliative care programs. The average program has been in



Table 1 Survey results

Group	Question	All leaders	Programs ≤5 years	Programs >5 years old	p^{a}
		Combined	(n=17)	(n=44)	
All programs	Q4: Specific palliative care (PC) services offered				
	PC consultation/mobile team service	49 (80 %)	12 (71 %)	37 (84 %)	0.29
	PC/supportive care clinic	50 (82 %)	11 (65 %)	39 (89 %)	0.06
all programs all programs all programs	Dedicated PC acute care beds	38 (62 %)	8 (47 %)	30 (68 %)	0.15
	Institution operated hospice	15 (25 %)	3 (18 %)	12 (27 %)	0.52
	All of the first 3 services	30 (49 %)	5 (29 %)	25 (57 %)	0.09
All programs	Q5: Types of services offered	Combined (n=17) (n=44) c care (PC) services offered bible team service			
	leaders Old Combined (n=17) (n=44)	0.39			
	Assistance in obtaining advance directives	37 (61 %)	(n=17) (n=44) (n=17) (n=44) (n) 12 (71 %) 37 (84 %) (n) 11 (65 %) 39 (89 %) (n) 8 (47 %) 30 (68 %) (n) 5 (29 %) 25 (57 %) (n) 7 (41 %) 25 (57 %) (n) 8 (47 %) 29 (66 %) (n) 9 (53 %) 29 (66 %) (n) 15 (88 %) 36 (82 %) (n) 16 (94 %) 42 (95 %) (n) 15 (88 %) 39 (89 %) (n) 17 (100 %) 43 (98 %) (n) 18 (47 %) 28 (64 %) (n) 14 (88 %) 25 (58 %) (n) 2 (12 %) 18 (42 %) (n) 7 (41 %) 12 (27 %) (n) 6 (35 %) 17 (39 %) (n) 16 (94 %) 29 (66 %) (n) 16 (94 %) 29 (66 %) (n) 2 (12 %) 13 (30 %) (n) 2 (12 %) 10 (27 %) (n) 3 (18 %) 4 (9 %) (n) 4 (12 %) (n) 5 (21 %) 1 (2 %) (n) 6 (35 %) 4 (9 %) (n) 13 (76 %) 29 (66 %) (n) 2 (12 %) 1 (2 %) (n) 3 (18 %) 4 (9 %) (n) 2 (12 %) 1 (2 %) (n) 3 (18 %) 4 (9 %) (n) 2 (12 %) 1 (2 %) (n) 3 (18 %) 4 (9 %) (n) 2 (12 %) 1 (2 %) (n) 3 (18 %) 4 (9 %) (n) 4 (24 %) 11 (25 %) (n) 5 (29 %) 6 (14 %) (n) 6 (35 %) 15 (34 %) (n) 15 (88 %) 39 (91 %) (n) 2 (12 %) 12 (27 %) (n) 15 (88 %) 39 (91 %) (n) 2 (12 %) 12 (27 %) (n) 15 (88 %) 39 (91 %) (n) 2 (12 %) 12 (27 %) (n) 15 (88 %) 39 (91 %) (n) 2 (12 %) 4 (9 %)	0.24	
	Assistance in resolving complex ethical issues	38 (62 %)	9 (53 %)	(n=44) %) 37 (84 %) %) 39 (89 %) %) 30 (68 %) %) 12 (27 %) %) 25 (57 %) %) 29 (66 %) %) 36 (82 %) %) 37 (84 %) %) 42 (95 %) %) 39 (89 %) %) 43 (98 %) %) 28 (64 %) %) 12 (27 %) %) 13 (30 %) %) 17 (39 %) %) 13 (30 %) %) 17 (39 %) %) 29 (66 %) %) 9 (20 %) %) 4 (9 %) %) 4 (9 %) %) 4 (9 %) %) 1 (2 %) %) 1 (2 %) %) 1 (2 %) %) 1 (2 %) %) 1 (2 %) %) 1 (2 %) %) 3 (7 %) %) 1 (2 %) %) 4 (9 %) %) 3 (7 %) %) 1 (2 %) %) 4 (9 %) %) 3 (7 %) %) 1 (2 %) %) 3 (7 %) %) 1 (2 %) %) 3 (7 %) %) 3 (7 %) %) 1 (2 %) %) 3 (7 %) %) 3 (7 %) %) 39 (91 %) %) 4 (9 %) %) 39 (91 %) %) 4 (9 %) %) 15 (36 %) %) 15 (36 %) %) 15 (36 %) %) 15 (36 %) %) 15 (36 %) %) 21 (50 %)	0.39
	Assistance with referrals to hospice, etc.	51 (84 %)	15 (88 %)	36 (82 %)	0.71
	Comprehensive care plan	51 (84 %)	14 (82 %)	37 (84 %)	1.0
	Pain consultation	58 (95 %)	16 (94 %)	42 (95 %)	1.0
	Psychosocial support	54 (89 %)	15 (88 %)	39 (89 %)	1.0
	Symptom management	60 (98 %)	17 (100 %)	43 (98 %)	1.0
	7–8 services	36 (59 %)	8 (47 %)	28 (64 %)	0.26
All programs	Q6: % pediatrics				
	0	39 (66 %)	14 (88 %)	25 (58 %)	
	$>0_{ m p}$	20 (34 %)	2 (12 %)	18 (42 %)	0.06
All programs	Q7: Professional background of program leaders				
	Anesthesia	19 (31 %)	7 (41 %)	12 (27 %)	0.36
	Family medicine	15 (25 %)	2 (12 %)	13 (30 %)	0.20
	Internal medicine	23 (38 %)	6 (35 %)	17 (39 %)	1.0
	Medical oncology	45 (74 %)	16 (94 %)	29 (66 %)	0.03
	Nursing	15 (25 %)	6 (35 %)	9 (20 %)	0.32
	Palliative medicine	31 (51 %)	9 (53 %)	22 (50 %)	1.0
	Pediatrics	3 (5 %)	2 (12 %)	1 (2 %)	0.19
	Psychiatry	7 (11 %)	3 (18 %)	4 (9 %)	0.39
	Radiation oncology	10 (16 %)	6 (35 %)	4 (9 %)	0.02
	Surgery		2 (12 %)	3 (7 %)	0.61
	Other	3 (5 %)	2 (12 %)	1 (2 %)	1.0
		42 (69 %)	13 (76 %)	29 (66 %)	0.54
All programs	Q8: No. of ward nurses assigned to PC				
	0				
				15 (34 %)	
			4 (24 %)	11 (25 %)	
		14 (23 %)	2 (12 %)	12 (27 %)	0.11
All programs					
				39 (91 %)	
	>5 ^d	6 (10 %)	2 (12 %)	4 (9 %)	1.0
All programs	Q10: No. of chaplains assigned to PC				
	0	20 (34 %)	5 (29 %)		
	1	27 (46 %)	6 (35 %)		
	2–5	12 (20 %)	6 (35 %)	6 (14 %)	0.19
All programs	Q11: No. of dietitians assigned to PC				
	0	20 (33 %)	7 (44 %)	13 (30 %)	



Table 1 (continued)

Group	Question	All leaders	Programs ≤5 years old	Programs >5 years old	p ^a
		Combined	(n=17)	(n=44)	
	1	33 (55 %)	8 (50 %)	25 (57 %)	
	2–5	7 (12 %)	1 (6 %)	6 (14 %)	0.25
All programs	Q12: No. of mid-level providers assigned to PC				
	0	17 (29 %)	6 (40 %)	11 (26 %)	
	1	12 (21 %)	4 (27 %)	8 (19 %)	
	2–5	20 (34 %)	3 (20 %)	17 (40 %)	
	>5 ^e	9 (16 %)	2 (13 %)	7 (16 %)	0.21
All programs	Q13: No. of PC physicians assigned to PC				
	$0-1^{\mathrm{f}}$	8 (13 %)	3 (18 %)	5 (12 %)	
	2–5	41 (68 %)	11 (65 %)	30 (70 %)	
	>5 ^f	11 (18 %)	3 (18 %)	8 (19 %)	0.67
All programs	Q14: No. of rehab. personnel assigned to PC				
	0	28 (47 %)	7 (44 %)	21 (48 %)	
	1	17 (28 %)	5 (31 %)	12 (27 %)	
	2–5	15 (25 %)	4 (25 %)	11 (25 %)	0.87
All programs	Q15: No. of pharmacists assigned to PC				
	0	32 (54 %)	9 (60 %)	23 (52 %)	
	$>0^{\mathrm{g}}$	27 (46 %)	6 (40 %)	21 (48 %)	0.77
All programs	Q16: No. of psychiatrists assigned to PC				
	0	32 (56 %)	9 (56 %)	23 (56 %)	
	1	25 (44 %)	7 (44 %)	18 (44 %)	1.0
All programs	Q17: No. of psychologists assigned to PC				
	0	7 (12 %)	1 (6 %)	6 (14 %)	
	1	32 (54 %)	8 (50 %)	24 (56 %)	
	2–5	20 (34 %)	7 (44 %)	13 (30 %)	0.26
All programs	Q18: No. of social workers assigned to PC				
	0	9 (16 %)	1 (6 %)	8 (19 %)	
All programs All programs All programs All programs All programs	1	30 (52 %)	10 (63 %)	20 (48 %)	
	>1 ^h	19 (33 %)	5 (31 %)	14 (33 %)	0.59
All programs	Q19: No. of other personnel assigned to PC				
All programs All programs	0	20 (34 %)	5 (31 %)	15 (36 %)	
	1	12 (21 %)	5 (31 %)	7 (17 %)	
	>1 ⁱ	26 (45 %)	6 (38 %)	20 (48 %)	0.83
All programs	Q20: FTE physician positions available to PC				
	Median (range)	2 (0–15)	2 (0–15)	2 (0–14)	0.33
All programs	Q21: No. of physicians with ≥20 % protected time				
	0	27 (45 %)	10 (63 %)	17 (39 %)	
	1	12 (20 %)	3 (19 %)	9 (20 %)	
	2–3	10 (17 %)	1 (6 %)	9 (20 %)	
	4-9	11 (18 %)	2 (12 %)	9 (20 %)	0.11
All programs	Q22: M.D. certification (finished a fellowship) required?	0.5 / 1.5		21 (12 2)	
	No	25 (42 %)	4 (25 %)	21 (48 %)	
4.11	Yes	35 (58 %)	12 (75 %)	21 (52 %)	0.15
All programs	Q23: Nursing certification (taken boards) required?	00 (45 0)	F (01 00	22 (52 24)	
	No	28 (47 %)	5 (31 %)	23 (52 %)	



Table 1 (continued)

Group	Question	All leaders	Programs ≤5 years old	Programs >5 years old	p^{a}
		Combined	(n=17)	(n=44)	
	Yes	32 (53 %)	11 (69 %)	21 (48 %)	0.24
All programs	Q24: How long does the PC team follow patients?				
	≤4 weeks ^j	15 (25 %)	3 (19 %)	12 (27 %)	
All programs	>4 weeks (includes "throughout the course of the patient's disease) ^j	45 (75 %)	13 (81 %)	32 (73 %)	0.74
An programs	No	15 (26 %)	6 (28 %)	0 (21 %)	
	Yes				0.31
Dedicated acute care beds	Q26: Number of PC beds	T3 (/T /0)	10 (02 70)	33 (17 70)	0.51
Dedicated acute care ocus	Median (range)	10 (0_43)	9 (5_30)	10 (0_43)	0.98
Dedicated acute care beds	· ·	10 (0 43)	7 (3-30)	10 (0 43)	0.76
Dedicated acute care ocus	No	11 (26 %)	3 (30 %)	8 (25 %)	
	Yes	` /	` ′	` ′	1.0
Dedicated acute care beds		31 (/4 /0)	7 (70 70)	24 (73 70)	1.0
Bedicated acute care ocus	≤5 years	13 (32 %)	9 (100 %)	2 (6 %)	
	>5 years				_
Dedicated acute care beds	Q29: Inpatient PC discharges per month	27 (00 70)	· ·	27 (51.70)	
	Median (range)	24 (2–250)	19 (6–40)	25 (2–250)	0.33
Dedicated acute care beds	Q30: Median stay	- ()	-5 (0 10)	()	
	Median (range)	10 (3–98)	14.5 (8–98)	9.5 (3–96)	0.007
Dedicated acute care beds	Q31: Median days from admission to death ^k	()	- 1.0 (0 3 0)	, ii (c , i)	
	Median (range)	10.5 (3–55)	15 (5–37)	9 (3–55)	0.36
Dedicated acute care beds	Q32: Inpatient PC mortality rate	,	,	,	
	Median (range)	40 (2–99)	35 (5–93)	43 (2–99)	0.69
Dedicated acute care beds	Q33: Reasons for admission (%—median/range)	, ,	. ,	, ,	
	Death imminent	10 (0-90)	10 (1–80)	12 (0–90)	0.42
	Acute symptom management	60 (0–90)	50 (5–80)	60 (0–90)	0.47
	Psychosocial reasons	10 (0-50)	30 (0-40)	7.5 (0–50)	0.35
	Respite	5 (0-40)	10 (0-40)	5 (0-10)	0.29
	Other reasons	10 (0-100)	5 (0-14)	10 (0-100)	0.26
Dedicated acute care beds	Q34: Referral sources (%—median/range)				
	Intensive care unit	5 (0-30)	5 (0-30)	0 (0-20)	0.11
	Other inpatient units	Long does the PC team follow patients? Res 15 (25 %) 3 (19 %) 12 (27 %) Res (includes "throughout the course patients" diseases) 13 (81 %) 32 (73 %) 13 (81 %) 32 (73 %) 14 (74 %) 10 (62 %) 33 (79 %) 15 (26 %) 6 (38 %) 9 (21 %) 43 (74 %) 10 (62 %) 33 (79 %) 10 (10 43) 10 (62 %) 33 (79 %) 10 (10 43) 10 (62 %) 33 (79 %) 10 (10 43)	0.91		
	Emergency room	10 (0-60)	10 (0-50)	10 (0-60)	0.79
	Outpatient clinics	25 (0-90)	25 (0-79)	22.5 (0-90)	0.89
	Other hospitals	5 (0-50)	7.5 (0–10)	5 (0-50)	1.0
	Hospice	0 (0-50)	0 (0–5)	0 (0-50)	0.49
	Other	5 (0-70)	0 (0-40)	15 (0-70)	0.44
Dedicated acute care beds	Q35: % of patients that receive psychosocial assessments				
	≤75 % ¹	19 (45 %)	6 (60 %)	13 (41 %)	
	>75 %	23 (55 %)	4 (40 %)	19 (59 %)	0.47
Dedicated acute care beds	Q36: % of inpatients that have family conferences				
	≤75 % ^m	21 (50 %)	6 (60 %)	15 (47 %)	
	>75 %	21 (50 %)	4 (40 %)	17 (53 %)	0.72
Dedicated acute care beds	Q37: How often do oncologists attend family conferences?				
	$\leq 15 \%^{\text{n,o}}$	19 (45 %)	2 (20 %)	17 (53 %)	



Table 1 (continued)

Group	Question	All leaders	Programs ≤5 years old	Programs >5 years old	p^{a}
		Combined	(n=17)	(n=44)	
	26–75 %°	8 (19 %)	3 (30 %)	5 (16 %)	
	>75 %	15 (36 %)	5 (50 %)	10 (31 %)	0.11
Dedicated acute care beds	Q38: What % of patients with DNR orders?				
	≤75 % ^{n,p}	20 (49 %)	6 (60 %)	14 (45 %)	
	>75 %	21 (51 %)	4 (40 %)	17 (55 %)	0.48
All programs	Q39: Dedicated consultation service?				
	No	5 (8 %)	2 (12 %)	3 (7 %)	
	Yes	54 (92 %)	14 (88 %)	40 (93 %)	0.61
Dedicated consult. service	Q40: How often is it available?				
	<24/7 ^q	30 (57 %)	8 (57 %)	22 (56 %)	
	24/7	23 (43 %)	6 (43 %)	17 (44 %)	1.0
Dedicated consult. service	Q41: No. of referrals/month				
	Median (range)	25 (3–400)	15 (4-40)	30 (3-400)	0.04
Dedicated consult. service	Q42: No. of days from referral to death ^r				
	Median (range)	23 (7–97)	15 (10-40)	25 (7–97)	0.21
Dedicated consult. service	Q43: Referral sources				
	Emergency department	29 (54 %)	8 (57 %)	21 (53 %)	1.0
	Medical oncology	51 (94 %)	13 (93 %)	38 (95 %)	1.0
	Surgery	40 (74 %)	11 (79 %)	29 (73 %)	0.74
	Hematology	34 (63 %)	7 (50 %)	27 (68 %)	0.34
	Radiation oncology	42 (78 %)	11 (79 %)	31 (78 %)	1.0
	Other	23 (43 %)	5 (36 %)	18 (45 %)	0.75
All programs	Q44: Patients seen in the outpatient setting?				
	No	10 (17 %)	5 (31 %)	5 (12 %)	
	Yes—dedicated PC outpatient clinic only	27 (46 %)	4 (25 %)	23 (53 %)	
	Yes—seen in oncology clinics only	11 (19 %)	5 (31 %)	6 (14 %)	
	Both	11 (19 %)	2 (13 %)	9 (21 %)	0.07
Patients seen in outpatient	Q45: How many days/week is the clinic held?				
setting	Median (range)	5 (0.5–7)	5 (2-7)	5 (0.5–7)	0.87
Patients seen inoutpatient	Q46: No. of referrals per month				
setting	Median (range)	30 (3–250)	17.5 (3–40)	30 (5–250)	0.01
Patients seen in outpatient	Q47: No. of days from referral to death ^s				
setting	Median (range)	40 (5–365)	40 (30–182)	37.5 (5–365)	0.58
Patients seen in outpatient	Q48: Referral Sources				
setting	Emergency department	15 (31 %)	4 (36 %)	11 (29 %)	0.72
	Medical oncology	46 (94 %)	11 (100 %)	35 (92 %)	1.0
	Surgery	32 (65 %)	8 (73 %)	24 (63 %)	0.73
	Hematology	29 (59 %)	6 (55 %)	23 (61 %)	0.74
	Radiation oncology	42 (86 %)	9 (82 %)	33 (87 %)	0.65
	Other	15 (31 %)	4 (36 %)	11 (29 %)	0.72
All Programs	Q49: Does your institution operate a hospice		•	•	
-	No	46 (77 %)	13 (81 %)	33 (75 %)	
	Yes	14 (23 %)	3 (19 %)	11 (25 %)	0.74
Programs with a hospice	Q50: Average hospice daily census		•	•	
•	Median (range)	Only 6 respor	ises		



Table 1 (continued)

Group	Question	All leaders	Programs ≤5 years old	Programs >5 years old	p^{a}
		Combined	(n=17)	(n=44)	
All programs	Q51: Palliative medicine Fellowship program?				
	No	36 (63 %)	12 (86 %)	24 (56 %)	
	Yes	21 (37 %)	2 (14 %)	19 (44 %)	0.06
Programs with pall.	Q52: No. of clinical fellows/year				
med. fellowship	1–2	11 (52 %)	1 (50 %)	10 (53 %)	
	>2 ^t	10 (48 %)	1 (50 %)	9 (47 %)	1.0
Programs with pall.	Q53: No. of research fellows/year				
med. fellowship	0	7 (44 %)	-0-	7 (50 %)	
	1	6 (38 %)	1 (50 %)	≤5 years	
	2	3 (19 %)	1 (50 %)	2 (14 %)	0.14
All programs	Q54: Mandatory PC rotations for med onc/hem fellows?				
	No	21 (36 %)	5 (31 %)	16 (37 %)	
	Yes				0.31
	Not applicable				1.0 ^u
All programs	Q55: Mandatory PC rotations for radiation one fellows?	, ,			
1 0	No	29 (49 %)	9 (56 %)	20 (47 %)	
	Yes				0.14
	Not applicable	` /			0.13 ^u
All programs		, ,	,	,	
	No	31 (54 %)	9 (60 %)	22 (52 %)	
	Yes				0.55
			6 (40 %)		0.55 ^u
All programs		(,,,,,	(11,70)	-, (10 ,0)	
F S		28 (49 %)	6 (40 %)	22 (52 %)	
		` /			0.27
					1.0 ^u
All programs		11 (20 70)	0 (10 70)	0 (17 70)	1.0
med. fellowship rograms with pall. med. fellowship Il programs Il programs		22 (38 %)	8 (50 %)	14 (33 %)	
	Yes			0.03	
					0.04 ^u
All programs		13 (22 70)	0 (30 70)	7 (17 70)	0.01
7 III programs		22 (39 %)	9 (60 %)	13 (32 %)	
All programs All programs All programs All programs Programs with PC grand					0.07
All programs		34 (01 /0)	0 (40 70)	28 (08 70)	0.07
7th programs		27 (47 %)	8 (53 %)	19 (44 %)	
					0.56
Programs with PC grand		31 (33 70)	7 (47 70)	24 (30 70)	0.50
		21 (68 %)		4 (57 %) 17	
	1	21 (00 70)			
	2	4 (13 %)	2 (29 %)		
	3	6 (19 %)	1 (14 %)	5 (21 %)	0.84
All programs	Q62: Length of training for fellows in certification				
	≤1 year ^v	24 (67 %)	8 (89 %)	16 (59 %)	
	>1 year ^v		1 (11 %)	11 (41 %)	0.22
All programs	-	. ,			
	No	35 (60 %)	10 (62 %)	25 (60 %)	



Table 1 (continued)

Group	Question	All leaders	Programs ≤5 years old	Programs >5 years old	p^{a}
		Combined	(n=17)	(n=44)	
	Yes	23 (40 %)	6 (38 %)	17 (40 %)	1.0
All programs	Q64: Recognized accreditation requirements				
	No	30 (52 %)	6 (40 %)	24 (56 %)	
	Yes	28 (48 %)	9 (60 %)	19 (44 %)	0.37
All programs	Q65: Is there a research program in PC				
	No	21 (36 %)	6 (40 %)	>5 years old (n=44) 17 (40 %) 24 (56 %) 19 (44 %) 15 (35 %) 28 (65 %) 7 (25 %) 6 (21 %) 4 (14 %) 20 (71 %) 20 (71 %) 5 (18 %) 15 (54 %) 9 (32 %) 11 (39 %) 17 (61 %) 8 (29 %) 10 (50 %) 12 (60 %) 10 (50 %) 12 (60 %) 10 (50 %) 15 (54 %) 16 (80 %) 17 (61 %) 16 (57 %) 2 (7 %) 7 (25 %) 13 (46 %) 13 (46 %) 13 (46 %) 15 (59 %) 15 (54 %) 17 (51 %) 16 (57 %) 17 (51 %) 18 (29 %) 19 (25 %) 11 (346 %)	
	Yes	37 (64 %)	9 (60 %)	28 (65 %)	0.76
Programs with research	Q66: Research team				
	Chaplains	8 (22 %)	1 (12 %)	7 (25 %)	0.65
	Pharmacists	9 (25 %)	3 (38 %)	6 (21 %)	0.38
	Rehab therapists	5 (14 %)	1 (12 %)	4 (14 %)	1.0
	Data analysts	27 (75 %)	7 (88 %)	20 (71 %)	0.65
	Physicians	36 (100 %)	8 (100 %)	28 (100 %)	1.0
	Research nurses	26 (72 %)	5 (62 %)	21 (75 %)	0.66
	Dieticians	6 (17 %)	1 (12 %)	5 (18 %)	1.0
	Psychologists	20 (56 %)	5 (62 %)	15 (54 %)	0.71
	Social workers	11 (31 %)	2 (25 %)	9 (32 %)	1.0
	Full team (physicians, research nurses, data analysts, psych/soc±others)	16 (44 %)	5 (62 %)	11 (39 %)	
	<full td="" team<=""><td>20 (56 %)</td><td>3 (38 %)</td><td>17 (61 %)</td><td>0.42</td></full>	20 (56 %)	3 (38 %)	17 (61 %)	0.42
Programs with research	Q67: Outside funding?				
	No	14 (38 %)	6 (67 %) 8 (29 %)		
	Yes	23 (62 %)	3 (33 %)	20 (71 %)	0.06
Programs with research	Q68: Sources of funding				
and funding	Private industry	12 (52 %)	2 (67 %)	10 (50 %)	1.0
	Institutional	12 (52 %)	-0-	dd (1) (n=44) 6 (38 %) 17 (40 %) 6 (40 %) 24 (56 %) 9 (60 %) 19 (44 %) 6 (40 %) 28 (65 %) 1 (12 %) 7 (25 %) 3 (38 %) 6 (21 %) 1 (12 %) 4 (14 %) 7 (88 %) 20 (71 %) 8 (100 %) 28 (100 %) 5 (62 %) 21 (75 %) 1 (12 %) 5 (18 %) 5 (62 %) 15 (54 %) 2 (25 %) 9 (32 %) 5 (62 %) 11 (39 %) 3 (38 %) 17 (61 %) 6 (67 %) 8 (29 %) 3 (33 %) 20 (71 %) 2 (67 %) 10 (50 %) -0- 12 (60 %) 1 (33 %) 10 (50 %) 3 (100 %) 16 (80 %) 7 (78 %) 25 (89 %) 6 (67 %) 15 (54 %) 2 (22 %) 17 (61 %) 4 (44 %) 16 (57 %) -0- 2 (7 %) 2 (22 %) 7 (25 %) 3 (33 %) 13 (46 %) 4 (44 %) 8 (29 %) 5 (56 %) 8 (29 %) 4 (44 %) 8 (29 %)	0.09
	Peer reviewed	11 (48 %)	1 (33 %)		1.0
	Private foundation/philanthropy	19 (83 %)	3 (100 %)	16 (80 %)	1.0
Programs with research	Q69: Types of research				
	Prospective studies	32 (86 %)	7 (78 %)	25 (89 %)	0.58
	Retrospective studies	21 (57 %)	6 (67 %)	15 (54 %)	0.70
	Case series/reports	19 (51 %)	2 (22 %)	17 (61 %)	0.06
	Qualitative studies	20 (54 %)	4 (44 %)	16 (57 %)	0.70
	Other	2 (5 %)	-0-	2 (7 %)	1.0
Programs with research	Q70: No. of abstracts presented at oncology conferences				
	0	9 (24 %)			
	1–2	16 (43 %)			
	$3-10^{w}$	12 (32 %)	4 (44 %)	8 (29 %)	0.52
Programs with research	Q71: No. of abstracts presented at PC conferences				
	0	13 (35 %)			
	1–2	12 (32 %)	4 (44 %)	9(32 %) 11 (39 %) 11 (39 %) 17 (61 %) 8 (29 %) 20 (71 %) 10 (50 %) 12 (60 %) 10 (50 %) 16 (80 %) 15 (54 %) 17 (61 %) 2 (7 %) 16 (57 %) 2 (7 %) 13 (46 %) 8 (29 %) 8 (29 %) 8 (29 %) 9 (8 (29 %)	
	>2 ^x	12 (32 %)	-0-	12 (43 %)	0.03
Programs with research	Q72: No. of abstracts presented at other meetings 0	9 (25 %)	2 (22 %)	7 (26 %)	
		(•)	()	/	



Table 1 (continued)

Group	Question	All leaders	Programs ≤5 years old	Programs >5 years old	p^{a}
		Combined	(n=17)	>5 years old (n=44) 18 (67 %) 2 (7 %) 8 (29 %) 10 (36 %) 10 (36 %) 11 (39 %) 17 (61 %) 11 (39 %) 13 (50 %) 2 (8 %) 2 (8 %) 2 (8 %) 16 (57 %) 8 (29 %) 10 (36 %) 9 (32 %) 9 (33 %) 17 (65 %) 17 (65 %) 8 (29 %) 9 (32 %) 9 (34 %) 9 (35 %) 9 (32 %) 9 (32 %) 9 (32 %) 9 (32 %) 9 (32 %) 9 (34 %) 9 (32 %)	
	1–5	23 (64 %)	5 (56 %)	18 (67 %)	
	>5 ^y	4 (11 %)	2 (22 %)	2 (7 %)	0.42
Programs with research	Q73: No. of papers published in oncology journals				
	0	12 (32 %)	4 (44 %)	8 (29 %)	
	1–2	11 (30 %)	1 (11 %)	10 (36 %)	
	>2 ^z	14 (38 %)	4 (44 %)	10 (36 %)	0.83
Programs with research	Q74: No. of papers published in PC journals				
	0	11 (30 %)	4 (44 %)	7 (25 %)	
	1–2	15 (41 %)	5 (56 %)	10 (36 %)	
	>2 ^{aa}	11 (30 %)	-0-	11 (39 %)	0.05
Programs with research	Q75: No. of papers published in general medical journals				
	0	19 (51 %)	2 (22 %)		
	>0 _{pp}	18 (49 %)	7 (78 %)	11 (39 %)	0.06
Programs with research	Q76: At what stage do you see cancer patients				
	At diagnosis				
	During curative therapy				
	During palliative therapy				
	After anticancer therapy is finished		-0-		
	When actively dying	3 (9 %)	1 (11 %)	2 (8 %)	0.23
Programs with research	Q77: Internal meetings PC members attend				
	Oncology conferences				1.0
	Oncology tumor boards			` /	0.46
	Oncology administrative meetings				0.71
	Oncology out- or inpatient meetings				0.70
	All 4 types	10 (27 %)	2 (22 %)	8 (29 %)	1.0
Programs with research	Q78: Do oncology members attend PC meetings/ conferences?				
	Palliative medicine lectures	27 (73 %)	7 (78 %)	20 (71 %)	1.0
	Palliative medicine administrative meetings	` `			1.0
	Both			` '	0.69
Programs with research	Q79: Do oncologists attend PC services?				
	No	11 (31 %)	2 (25 %)	9 (33 %)	
	Yes	24 (69 %)	6 (75 %)	18 (67 %)	1.0
Programs with research	Q80: Do PC specialists attend oncology services?				
	No	11 (31 %)	2 (22 %)	9 (35 %)	
	Yes	24 (69 %)	7 (78 %)	17 (65 %)	0.69
Programs with research	Q81: Is there integration of PC with other departments?				
	Intensive care	11 (30 %)	3 (33 %)	8 (29 %)	1.0
	Geriatrics	11 (30 %)	2 (22 %)	9 (32 %)	0.69
	Cardiology	4 (11 %)	1 (11 %)	3 (11 %)	1.0
	Neurology	8 (22 %)	2 (22 %)	6 (21 %)	1.0
	Pulmonology	11 (30 %) 1 (11 %) 1 14 (38 %) 4 (44 %) 1 11 (30 %) 4 (44 %) 1 15 (41 %) 5 (56 %) 1 11 (30 %) -0- 1 19 (51 %) 2 (22 %) 1 18 (49 %) 7 (78 %) 1 8 (23 %) 2 (22 %) 1 15 (43 %) 2 (22 %) 1 2 (6 %) -0- 2 3 (9 %) 1 (11 %) 2 24 (65 %) 6 (67 %) 1 20 (54 %) 6 (67 %) 1 19 (51 %) 4 (44 %) 1 20 (54 %) 4 (44 %) 1 20 (54 %) 4 (44 %) 1 10 (27 %) 2 (22 %) 8 27 (73 %) 7 (78 %) 1 13 (35 %) 3 (33 %) 1 11 (30 %) 2 (22 %) 9 11 (31 %) 2 (22 %) 9 11 (31 %) 2 (22 %) 9 11 (31 %) 2 (22 %) 9 11 (31 %) 2 (22 %) 9 11 (31 %) 2 (22 %) 9 11 (31 %) 2 (22 %) 9 11 (31 %) 2 (22 %) 9 11 (31 %) 1 (11 %) 3 11 (30 %) 3 (33 %) 8 11 (30 %) 3 (32 %) 8 11 (30 %) 3 (33 %) 8 11 (30 %) 3 (33 %) 8 11 (30 %) 3 (33 %) 8 11 (30 %) 3 (33 %) 8 11 (30 %) 3 (33 %) 8 11 (30 %) 3 (33 %) 8 11 (30 %) 3 (33 %) 8 11 (30 %) 3 (33 %) 8 11 (30 %) 3 (33 %) 8 11 (30 %) 3 (33 %) 8 11 (30 %) 3 (33 %) 8 11 (30 %) 3 (33 %) 8 11 (30 %) 3 (33 %) 8 11 (30 %) 3 (33 %) 8 11 (30 %) 3 (33 %) 8 11 (30 %) 3 (33 %) 8	8 (29 %)	1.0	
	Pediatrics	4 (11 %)	-0-	4 (14 %)	0.55
Programs with research	Pain medicine	18 (49 %)	4 (44 %)	14 (50 %)	1.0



Table 1 (continued)

Group	Question	All leaders Combined	Programs ≤5 years old (<i>n</i> =17)	Programs >5 years old (n=44)	p^{a}
	Rehabilitation	8 (22 %)	3 (33 %)	5 (18 %)	0.37
	Other ^{cc}	4 (11 %)	-0-	4 (14 %)	0.53

^a Fisher's exact test for factors with two levels, chi-square test for unordered categorical factors with >2 levels, Cochran-Armitage trend test for ordered categorical factors, Wilcoxon rank sum test for measured factors

existence greater than 5 years and has multiple services (inpatient, inpatient consultative, and outpatient). These programs have a limited number of nurses dedicated to palliative care and their leaders have an oncology background plus an addition specialty. Programs usually consist of two full-time physicians who follow patients through the trajectory of illness, manage 10 inpatients, see inpatient and outpatient consults daily, perform a large variety of tasks, and provide teaching in the form of Grand Rounds. A subset will also have fellowship programs with extra responsibilities. Subsets also do research, usually with less than fully staffed research services. More mature programs see more patients, have shorter hospital length of stays and interact with greater

frequency with other specialties than oncology. Most programs do publish in peer review journals. This survey did not include administration time, local meetings, and national or international organization responsibilities.

Standardized definitions of palliative care are lacking and the term palliative care has little or no meaning to patients [1]. The use of the term palliative care may put patients off from accepting services as discussed in recent publications from the USA [9, 10]. Symptom management in this setting is largely supportive.

Different palliative care service models are present throughout Europe. Day care centers are largely present in the UK and hence were excluded from the survey. Palliative



^b 1–26, n=19; 26–50 %, n=1

 $^{^{\}circ}$ 11–25, n=11; 26–50, n=1; >50, n=2

^d 0, n=4; 1–5 n=50; 6–10, n=5, 11–25=1

 $^{^{}e}$ 6–10, n=5; >10, n=4

f(0, n=1; 1, n=7; 6-10, n=8; >10, n=3)

g = 1, n = 23; 2 - 5, n = 4

 $^{^{\}text{h}}$ 2–5, n=17; 6–10, n=2

 $^{^{}i}2-5$, n=21; 6-10, n=5

^j 1–7 days, n=4; >1–4 weeks, n=11; >1–12 months, n=18, >2 years, n=1; throughout the course of the patient's illness—n=26

 $^{^{}k} n = 24$

 $^{^{1}}$ 0, n=0; 1–25 %, , n=4; 26–50 %, n=7; 51–75 %, n=8

 $^{^{}m}$ 0, n=0; 1–25 %, n=6; 26–50 %, n=6; 51–75 %, n=9

^N survey form says 1–15 %, should be 1–25 %????

 $^{^{\}circ}$ 0, n=8; 1–15 %, n=11; 26–50, n=5; 51–75, n=3

 $^{^{}p}$ 0, n=1; 1–15 % (should be 1–25 %????), n=5; 26–50 %, n=6; 51–75 %, n=8

 $^{^{\}rm q}$ 24 h, weekdays only, n=3; business hours/weekdays, n=24; other (but not 24/7), n=3

 $^{^{\}rm r}$ n = 29

 $^{^{\}rm s} n = 21$

^t Median (range), 2 (1–22)

^u Yes vs. no

 $^{^{}v}$ <1 year, n=4; 2 years, n=7; 3 years, n=4; 5 years, n=1

 $^{^{\}text{w}}$ 3–5, n=11; 6–10, n=1

x = 3-5, n=8; 6-10, n=2; >10, n=2

 $^{^{9}}$ 6–10, n=2; >10, n=2

 $^{^{}z}$ 3-5, n=11; 6-10, n=2; >10, n=1

^{aa} 3–5, n=4; 6–10, n=3; >10, n=4

bb 1-2, n=14; 3-5, n=3; 6-10, n=1

cc Excludes oncology departments

care inpatient beds per million population range from >5 to >1 depending on the region or country. The number of palliative care specialists range from 1 per 100,000 to 1 per 1.6 million population [11].

Challenges to palliative care structures and service are prioritization based on both the oncologist and patient perspective. Since the greatest advantage to palliative care services occurs when utilized early in the course of advanced cancer as reported in the USA, outpatient clinics and availability are key [4, 12]. Shared care is primarily achieved through outpatient clinics. Inpatient consultation services and inpatient palliative care units are largely centered on crisis intervention. Multidisciplinary palliative care team values are largely measured by indirect cost savings.

Palliative care as an element of cancer care requires a medical oncologist dedicated to palliative care [13]. The key to success is collaboration, commitment, continuity, communication, and patient centeredness. To achieve this goal, palliative care programs need to be available with multiple service lines in order to provide continuity. Oncologists need to continue to be involved with patients on palliative care units to provide input as to disease course, availability, and appropriateness of further anti-cancer therapy and to communicate with families about goals of care within family conferences.

Palliative care services are underfunded for education and research. Only 1/3 of programs have fellowship training programs. Grant support is largely from private foundations or philanthropic donations rather than governmental sources.

Although there are no universally embraced quality indicators for the organization of palliative care, a number of quality indicators were generated from a Europall project systematic review [14]. These quality indicators include 24/7 availability of the consultative team, a staff that includes a pharmacist, and a single caregiver that can coordinate care to provide continuity across service lines. All team members should be accredited and a psychosocial assessment along with symptom assessment should occur within 24 h of admission to a palliative care unit. Palliative care programs should have quality assurance, research and fellowship programs [14]. In this regard, many programs fall short in one or more areas.

Educational exchanges between adult and pediatric palliative specialties are very limited. This may be largely due to different cancers and in types of terminal diseases and perhaps different symptom management strategies. The psychosocial stressors and clinical problems are distinctly different. There is probably limited value for pediatric palliative fellows to rotate on adult services.

There are differences between the present study and the survey reported by Dr. Hui [8]. The majority of programs in the present survey have been in existence for 5 years compared with programs surveyed by Dr. Hui (43 of 62, 70 % vs. 39 of 96 or 41 %). More programs surveyed in the present

study followed patients in continuity (4 weeks or greater) than in the study published by Dr. Hui (45 of 62.73 % vs. 26 of 96.27 %). Half of programs surveyed in both studies required physician certification in palliative medicine. Most leaders of palliative programs in the present study were oncologists with additional specialty training (74 %) whereas in the Hui study only 17 % had an oncology background. The great majority of palliative programs in both surveys had consultative services. However, only a minority provided a 24-h-7 day-a-week consultative service. The median time from inpatient consultative referral to death was 23 days in the present study and 7 days in the Hui study. Most programs in the present study had inpatient palliative care beds (38/62, 61 %) whereas most programs in the Hui study did not have dedicated beds (27/96, 28 %). Median length of stay in hospital was 10 days in both studies. The death rate on the inpatient palliative care units was 40 % in both studies. Dedicated palliative outpatient clinics were available in approximately half of programs reported in both studies. Approximately 20 % of programs had palliative specialists participate in oncology clinics. However, the time from referral to death in the present study was 40 days and in the Hui study 90 days. Palliative care clinics were available 5 days a week in the present study and 2 days a week in the Hui study. Referrals to outpatient palliative care clinics were greater the present study then programs surveyed by Dr. Hui (30 per month vs. 7–14 per month). Less than half of programs had palliative fellowships. Mandatory oncology fellow rotations in palliative care were greater in the programs surveyed in the present study (46 %) than in the Hui study (22-27 %). This was also true of medical student rotations (26 % vs. 12-13 %). Nearly 2/3 of programs (64 %) in the present study had research as part of the program structure whereas less than half (46 %) of programs in the Hui study were involved with research. The difference between programs may be the result of the ESMO designated palliative programs surveyed in the present study which are required to have a well-developed palliative program integrated into oncology for ESMO recognition. Differences also may reflect differences in palliative care philosophy, service structure and referral between Europe and the USA.

There are several weaknesses of this study. Palliative programs surveyed were largely western European. Responders were likely to be from well-established palliative programs probably embedded in cancer centers. The results would likely to be different if rural and community hospital programs were surveyed. Survey results were influenced by those willing to complete them on line and will likely reflect well-developed programs. We did not query program leaders about financial support of their programs. Questions 76–81 were completed by programs with research structures, though the questions were intended for all completing the survey. This would have skewed the results. The program activity data was largely based on approximate estimates as it is not known how many



of these programs maintain ongoing quality assurance data to provide more accurate responses.

Conclusions

Palliative care consists of multiple service lines which provide continuity throughout the course of cancer. Patients are usually seen late in the course of their illness as demonstrated by a high death rate on inpatient palliative care units and short survival in patients seen as outpatients. In general, palliative care is under resourced.

Conflicts of interest The authors have no conflicts of interest.

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