The Current State of Palliative Care for Patients Cared for at Leading US Cancer Centers: The 2015 NCCN Palliative Care Survey

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Abstract

Background: ASCO and IOM recommend palliative care (PC) across health care settings for patients with serious illnesses, including cancer. This study provides an overview of the current availability, structure, and basic quality of PC services within NCCN Member Institutions. **Methods:** A PC survey was developed by NCCN staff and a working group of PC experts from 11 NCCN Member Institutions under the auspices of the NCCN Best Practices Committee. The survey was piloted and refined by 3 working group members and sent electronically to all 26 NCCN Member Institutions. NCCN staff and working group leaders analyzed the survey data. **Results:** A total of 22 of 26 institutions responded (85%). All respondents (100%) reported an inpatient PC consult service (staffed by an average of 6.8 full-time equivalents [FTEs], seeing 1,031 consults/year with an average length of stay [LOS] of 10 days). A total of 91% of respondents had clinic-based PC (with an average of 469 consults/year, staffed by an average of 6.8 FTEs, and a 17-day wait time). For clinics, a comanagement care delivery model was more common than strict consultation. Home-based PC (23%) and inpatient PC units (32%) were less prevalent. Notably, 80% of institutions reported insufficient PC capacity compared with demand. Across PC settings, referrals for patients with solid tumors were more common than for hematologic malignancies. Automatic or “triggered” referrals were rare. The most common services provided were symptom management (100%) and advance care planning (96%). Most programs were funded through fee-for-service billing and institutional support. Partnerships with accountable care organizations and bundled payment arrangements were infrequent. PC program data collection and institutional funding for PC research were variable across institutions. **Conclusions:** Despite the prevalence of PC inpatient and clinic services among participating NCCN Member Institutions, PC demand still exceeds capacity. Opportunities exist for expansion of home-based PC and inpatient PC units, optimizing referrals, research, and payer collaborations.

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Background

As data on the benefits of palliative care (PC) for patients with cancer accumulate,^{1–5} models for integrating PC into cancer centers have been proposed.⁶ Led by ASCO, the Commission on Cancer, and IOM,^{7–10} prominent professional organizations now recommend PC be integrated routinely into cancer care, particularly for patients with advanced disease. NCCN, an alliance of leading US cancer centers, features a clinical guide-

line on PC for patients with cancer and includes PC recommendations in other clinical guidelines.¹¹

Numerous studies suggest penetration and capacity of PC services, both inpatient and in the community, have not kept pace with recommendations, including for patients with cancer.^{12–17} Hui et al¹² surveyed cancer centers in 2010 and found inpatient PC services in 91% of NCI-designated comprehensive cancer centers and outpatient services in 59%. Prevalence in non-NCI-designated centers was much lower (56% inpatient and

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22% outpatient). In another study, 55% of patients seen at a comprehensive cancer center did not receive PC before death.¹⁸ No recent research has assessed adherence to recommendations for universal availability of PC for patients with advanced cancer.

Numerous organizations have recommended metrics to assess the quality of PC provided.^{19–21} However, data about the quality of PC provided to patients with cancer are limited, and much of these data are from single institutions.^{5,22–24}

To examine the current availability and basic quality of PC services for US patients with cancer, we surveyed NCCN Member Institutions regarding the prevalence, type, staffing, and financing of their PC programs. We also inquired about metrics, research, and education within their PC programs.

Methods

The NCCN Best Practices Committee (BPC) provides a forum for senior physician and administrative leaders from NCCN Member Institutions to collaborate, network, and share strategies aimed towards improving the effectiveness and efficiency of cancer center operations. The NCCN BPC promotes research studies for the purpose of benchmarking, determining best practices, and performance improvement. Each NCCN Member Institution appoints one representative to serve on the NCCN BPC.

The 2015 NCCN Palliative Care Survey was developed by NCCN staff with a working group of PC experts from 11 NCCN Member Institutions. The 2015 survey expanded on an initial BPC 2014 survey regarding PC programs. Working group members (WGMs; [see supplemental eAppendix 1, available with this article at JNCCN.org](#)) developed an extensive list of potential survey questions that could provide valuable data to PC and cancer center leaders. To develop the 2015 survey, WGM individually ranked the importance of each potential survey question on a 5-point scale. The first draft was piloted by 3 WGMs. The survey was revised based on their feedback and a second pilot was conducted with the same 3 WGMs. In April 2015, the final survey ([see supplemental eAppendix 2](#)) was sent electronically to all 26 NCCN Member Institutions with a request to complete the survey within 4 weeks. A reminder email was sent if no response was received after 4 weeks. The PC survey was sent to the NCCN BPC

with instructions to forward the survey to the staff most knowledgeable about that institution's PC services.

Survey data were analyzed jointly by NCCN staff and working group co-leaders (B.A.C. and M.W.R.) using descriptive statistics and group *t*-tests, without between-group comparisons. Statistical significance was a *P* value less than 0.05. Because the survey did not include patient-specific data and was intended for quality improvement purposes, the study was exempted from Institutional Review Board review from UCSF's Committee on Human Research.

Results

Response Rate

Of the 26 NCCN Member Institutions, 22 responded to the survey (85% response rate; [see supplemental eAppendix 3](#)).

Program Structure

The basic program structure is described in Table 1. Each institution reported an inpatient PC consultation service. The inpatient PC consultation programs were established between 1991 and 2012, with three-quarters beginning after 2005. An outpatient clinic established between 1981 and 2013 was reported by 20 institutions (91%), with three-quarters established in the last 10 years. A comanagement care delivery model (85% of clinics reported they do at least some comanagement) was more common than strict consultation (48% of clinics reported they do at least some consultation). For the purpose of this study, comanagement is defined as having PC providers actively prescribe and enact PC treatment plans alongside the patient's oncology team (concurrent with the oncologists' care), whereas strict consultation is providing treatment recommendations that the oncology team can then decide to enact. Inpatient PC or hospice units (32%) and home-based PC or mobile PC programs (23%) were less prevalent. Most inpatient PC or hospice units and home-based PC programs were established in 2010 or later.

Across PC settings, referrals for patients with solid tumors were more common than for those with hematologic malignancies. Of the 22 institutions responding, 17 (77.2%) reported that more than half of their referrals were for patients with solid tumors. In order of prevalence, patients with gastrointestinal cancers, thoracic cancers, breast cancers, and

Table 1. Palliative Care Program Characteristics Across Settings

Characteristic	% Answered Yes (Number of Respondents)
Palliative care service available	
Inpatient consultation	100 (22/22)
Clinic	91 (20/22)
Inpatient unit or hospice	32 (7/22)
Home-based/mobile	23 (5/22)
Referrals of patients with solid tumors (vs hematologic malignancies)	
<10%	0 (0/21)
10%–24%	10 (2/21)
25%–49%	10 (2/21)
50%–75%	33 (7/21)
≥75%	47 (10/21)
Automatic or “triggered” referrals	
Inpatient consult	14 (3/22)
Clinic	20 (4/20)
Home	20 (1/5)
Services provided	
Symptom management	100 (22/22)
Advance care planning	96 (21/22)
Bereavement services	64 (14/22)
Psycho-oncology	68 (15/22)
Survivorship support	59 (13/22)
Child-life services	50 (11/22)

hematologic malignancies were most often referred for inpatient PC consultation. Patients referred for outpatient PC services most often had diagnoses of gastrointestinal, breast, or thoracic cancers, followed by hematologic malignancies.

Automatic or “triggered” referrals were rare. Only 3 of 22 inpatient consultation programs (13.6%) and 4 of 22 outpatient clinic programs (18.2%) reported a mechanism for automatic referrals. Several programs cited a lack of PC capacity as an explanation for avoiding automatic referrals.

The most frequently perceived barriers to optimal PC referrals by oncologists were unfamiliarity with the scope of PC services, the perception that PC is already delivered in their own oncology clinics, and late PC referrals.

Across PC settings, our findings showed symptom management and advance care planning services were nearly universal. The availability of other

services, including psycho-oncology, child life services, bereavement services, and survivorship support, was more variable (Table 1).

Program Staffing, Demand, and Financing

Across PC settings, the mean $\pm$ standard deviation for physician and nurse practitioner full-time equivalent (FTE) staffing was 4.1 $\pm$ 2.9 and 2.8 $\pm$ 2.0, respectively. Nearly all institutions reported chaplain (mean FTE, 0.9 $\pm$ 0.9) and social work (mean FTE, 3.3 $\pm$ 5.6) support. Most programs also had nursing support (mean FTE, 1.6 $\pm$ 1.5). Notably, 80% of institutions reported insufficient PC capacity compared with demand.

Most programs were funded through fee-for-service billing and institutional support. Risk-based reimbursement methodologies (ie, Accountable Care Organization arrangements, global reimbursement, bundled payments) were rare. Roughly half (52%) of the institutions' PC programs covered the salaries of nonbilling providers.

Inpatient PC consultation staffing is described in Table 2. Inpatient consult services were staffed by an average of 6.8 FTEs (billing and nonbilling providers). They saw an average of 1,032 $\pm$ 557 unique consults per year (151.8 consults/FTE annually). The average length of stay on the consult service was 10 days.

Clinic-based PC staffing is described in Table 3. PC clinics saw an average of 469 $\pm$ 215 unique patients per year with an average staffing of 3.3 FTEs (142.1 new patients per FTE annually). Clinic visits were conducted by a mix of physicians and advance practice providers (APPs). A total of 19% of institutions reported clinic visits conducted by physicians only, 43% conducted jointly by both physicians and APPs, 10% by APPs only, and 29% listed “other” (including nurse visits, new visits with physician,

Table 2. Inpatient Palliative Care Consultation Characteristics

Characteristic	Mean [SD] (Number of Respondents)
Unique consults/year	1,031.5 [556.5] (22)
Length of stay in days	10 [5.2] (13)
Number of visits/patient	4.2 [4.1] (18)
Total staffing full-time equivalent ^a	6.8 [5.8] (21)

Advanced practice providers include nurse practitioners, advance practice nurses, and physician assistants.

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Table 3. Palliative Care Clinic Characteristics

Characteristic	% Answered Yes (No. of Respondents)
Clinic model	
Comanagement	85.7 (18/21)
Consultative	47.6 (10/21)
Other	14.3 (3/21)
PC embedded in oncology clinics (vs free-standing)	52 (11/21)
New patient appointment length	
15–30 min	0 (0/21)
45 min	5 (1/21)
60 min	76 (16/21)
75 min	10 (2/21)
90 min	5 (1/21)
Other	5 (1/21)
Outpatient follow-up patient appointment length	
15 min	0 (0/21)
30 min	71.4 (15/21)
45 min	14.3 (3/21)
60 min	4.8 (1/21)
Other	9.5 (2/21)
Process Measure	Mean [SD or range] (Number of Respondents)
Unique consults/year	468.8 [214.5] (21)
Number of visits/patient	4.1 [2.5] (18)
Wait time for new referrals	16.5 [range, 1.5–90 d] (19)
Total staffing full-time equivalent	3.3 (2.5)

Advanced practice providers include nurse practitioners, advance practice nurses, and physician assistants.

and follow-up with APPs). Most (76%) new patient clinic appointments were 60 minutes in length and most (71%) follow-up patient appointments were 30 minutes in length. Average wait time for new referrals was 17 +/- 21 days.

An average of 1.3 +/- 0.6 FTEs staffed the inpatient PC or hospice units (3 programs reporting). A total of 4 of the 7 programs that reported inpatient PC or hospice units provided information on number of consults per year. The average number of unique consults per year was 397 +/- 285, with a short length of stay (5 +/- 2 days). A total of 3 of 5 home-based PC programs reported staffing data. Home-based/mobile PC programs were staffed by an

average of 1.7 +/- 2 FTEs. The average number of unique consults per year was 114 +/- 9. There was insufficient data to accurately report wait times.

Most (61%) inpatient PC consultation programs and approximately half (47%) of clinic-based PC programs reported productivity expectations (typically relative value unit [RVU]–based). Productivity expectations were less common among inpatient PC/hospice units (25%) and home-based PC programs (20%).

Research, Quality Improvement, and Education

Data collection and review of PC program outcomes were variable (Table 4). All institutions collected data on PC program utilization. Approximately one-third of PC programs reported being directed by their institutions to impact specific health care utilization and Quality Oncology Practice Initiative (QOPI) outcomes. Half or fewer programs reported access to various health care utilization metrics at their institutions. Fewer than one-third (29%) of institutions reported any funding for their PC programs and/or providers to conduct research.

Most (68%, n=15) institutions compared their PC programs with national guidelines. In order of prevalence, the most frequently cited guidelines included those from the National Quality Form, Center to Advance Palliative Care (CAPC), NCCN, and QOPI.

A total of 77% of programs have a PC fellowship associated with their institution. Fellowships were established from 1997 to 2014, with 4 of the 17 fellowships established as recently as 2014. The number of PC fellows rotating in the institutions' PC programs was variable, with most institutions reporting 1 to 4 fellows, and 3 institutions (14%) reporting 5 or more fellows. Oncology fellows rotate much less frequently within PC. No oncology fellows rotated in PC in 41% of institutions, and 23% reported only one oncology rotator. A total of 41% of institutions noted some cancer center support to provide primary or "generalist" PC training within their cancer centers.

Discussion

Our survey provides current information on the availability, structure, and basic quality of PC services within NCCN Member Institutions. Inpatient PC services were universal among these institutions and outpatient clinic services were nearly so. Dedicated PC units and home-based services were much

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Table 4. Research and Quality Improvement

	% Answered Yes (Number of Respondents)
Palliative care has routine access to cancer center's data elements	
Hospital 30-day readmission rate for cancer-related admissions	50 (10/20)
Rate of cancer center patient death in hospital (defined as the proportion of all patients with cancer decedents who die in the hospital)	50 (10/20)
Average length of stay for inpatient patients with cancer	50 (10/20)
Percentage of patients receiving chemotherapy within last 2 weeks of life	30 (6/20)
Percent of discharges to hospice with hospice length of stay less than 3 days	30 (6/20)
Percentage of patients with advanced directive documented in the EMR	20 (4/20)
Palliative care directed by cancer center to impact outcome	
Percentage of patients with advanced directive documented in the EMR	55 (11/20)
Hospital 30-day readmission rate for cancer-related admissions	35 (7/20)
Average length of stay for inpatient patients with cancer	35 (7/20)
Percentage of patients receiving chemotherapy within last 2 weeks of life	35 (7/20)
Percent of discharges to hospice with hospice length of stay less than 3 days	30 (6/20)
Rate of cancer center patient death in hospital (defined as the proportion of all patients with cancer decedents who die in the hospital)	30 (6/20)
Palliative care program—collected data elements	
Program utilization/number referrals	100 (21/21)
Patient and/or family satisfaction	47.6 (10/21)
Patient utilization outcomes	33.3 (7/21)
Patient clinical outcomes	28.6 (6/21)
Referrer satisfaction	23.8 (5/21)
Other	4.8 (1/21)

Abbreviation: EMR, electronic medical record.

less common. The PC services at these cancer centers typically used a comanagement model, seeing primarily patients with solid tumors. Referrals were typically ad hoc rather than triggered by an objective measure of need. Staffing was typically interdisciplinary with inpatient teams seeing, on average, 151.8 consults per FTE per year, and clinics seeing 142.1 new patients per FTE per year. There was some variability in whether and how programs collect data on their services and whether, and which, national guidelines they follow. Educational services were limited, with relatively limited PC training for oncology fellows and limited primary PC educational activity.

The prior study by Hui et al,¹² which investigated availability and integration of PC services among NCI-designated and non-NCI cancer centers, provides the closest comparison to our data from NCCN Member Institutions. Keeping in mind potential differences between these institutions, it does appear that, compared with the data reported by Hui et al in

2010, the penetration of PC in cancer centers is likely increasing nationally, including in the outpatient setting. Most (91%) of the institutions in our study reported having an outpatient PC clinic. This percentage is in contrast to the 22% and 59% of US non-NCI and NCI cancer centers, respectively, reporting PC clinics in 2010. The number of patients seen by PC also appears to be increasing. NCI-designated cancer centers reported an average of 168 outpatient clinic PC referrals annually in 2010 versus 469 in our study. NCI-designated cancer centers reported an average of 576 inpatient PC consults annually in 2010 versus 1,032 in our study. The availability of inpatient PC and hospice units does not appear to have changed significantly since 2010 (32% in our study vs 30% for NCI-designated cancer centers). The number of PC physicians on staff was higher in our survey (mean of 4 FTEs) versus a median of 1 FTE in the study by Hui et al.¹² We lack sufficient data to compare nonphysician staffing between the studies.

The next frontier for expansion of PC services at cancer centers, particularly for the most vulnerable patients, is likely home-based PC.²⁵ Only 5 of the 22 NCCN Member Institutions reported a home-based PC program. We were unable to accurately characterize these programs given limited reported data. Additional research is needed to elucidate these programs' characteristics and home-based PC nationally.

Despite increased availability, demand for PC services continues to outpace supply. A striking 80% of surveyed institutions reported insufficient PC capacity to meet demand. This deficit is manifested by the long wait times reported for new patient PC clinic visits (17 +/- 21 days). The capacity shortfall is particularly concerning in light of the severity of illness and symptom burden of the cancer population. Financial limitations are a major cause of constricted capacity. In a study of European cancer centers, Davis et al²⁶ cited key barriers to PC, including budget constraints (or priorities), lack of trained personnel, and perceived poor reimbursement for services. Our study found that most programs continue to be supported primarily by fee-for-service reimbursement and institutional support. In the programs surveyed, risk-based reimbursement methodologies were infrequently used to finance PC programs. Strategies to engage payers to support PC services may help remedy program expansion limitations.

In addition to financial limitations, many institutions (43%) cited inadequate PC staffing as a significant barrier to provision of PC. Fortunately, the number of PC physician fellowships appears to be increasing. A total of 77% of institutions surveyed reported the presence of a PC fellowship versus 40% of NCI-designated cancer centers and 17% of non-NCI cancer centers in 2010.¹² Further elucidation of the characteristics of these fellowship programs and interprofessional training opportunities are needed.

Our study results highlight the need for additional non-PC provider training in primary or "generalist" PC. A recent Delphi study of PC-oncology integration experts identified 13 major criteria that would serve as markers of successful PC-oncology integration.²⁷ Of these major criteria, 4 related specifically to education, highlighting the critical role PC education should play in caring for patients with cancer. These 4 criteria were: PC didactic curriculum for oncology fellows, continuing medical education in PC for attending oncologists, combining

PC and oncology educational activities for fellows, and oncology fellow rotation on PC services. In our study, 40% of programs report no oncology fellow participation in PC services. In addition, only 41% of programs reported support for primary PC education (the details of the type of support is unknown). Taken together, these data highlight the need for the investment in primary PC education to effectively meet the PC needs of patients with cancer, and further integration of the PC and oncology fields.

Triggered referrals (ie, mandated PC referrals based on screening criteria such as disease status, symptom burden, and patient or caregiver characteristics) were not common. Only 14% of inpatient consultation programs and 21% of PC clinics reported using trigger criteria to target patients for PC. Potential explanations for this include current workforce limitations, implementation complexities, and the lack of standardized and validated criteria to trigger a referral. Several organizations, including CAPC and NCCN, have proposed screening criteria for PC involvement.^{28,29} However, few tools have been validated or assessed for feasibility.³⁰ A recent study found that only 10% of NCCN Member Institutions used any of the available NCCN Clinical Practice Guidelines in Oncology for Palliative Care to formally screen patients for PC, and of these identified patients, only 60% were ultimately referred to a PC specialist.³¹ Given current workforce issues, further evaluation of PC screening tools and trigger criteria are needed to ensure provision of earlier specialty-level PC services for patients most in need.

Consistent with previously published data, PC referrals for hematologic malignancy patients in our study were disproportionately low.³² Approximately 50% of programs reported that more than 75% of their referrals were for patients with solid tumors (as opposed to hematologic malignancies). LeBlanc et al³³ found that, compared with solid tumor oncologists, hematologic oncologists were more likely to view PC as end of life care and antithetical to cancer treatment. Further education and partnerships with hematologic oncologists are key to ensuring that these patients have access to specialty-level PC services.

Our study reinforces the need for ongoing efforts to align PC data collection and quality assurance measures nationally. Among NCCN Member Institutions, the quantity and type of PC data collected are variable. Similar diversity is found in programs'

selection of national PC quality guidelines. Streamlining program evaluation and quality improvement processes via participation in quality improvement collaboratives, such as the Palliative Care Quality Network,³⁴ and use of the Quality Data Collection Tool for Palliative Care³⁵ will prove helpful.

Our study had several limitations. We surveyed a small number of cancer centers, all of which were NCCN Member Institutions. This could limit the external generalizability of our results. Currently, there is no standardized method of data collection among the programs surveyed. Therefore, some of the data could have been inaccurate or biased, depending on the data available to each PC program and how the survey questions were interpreted. Although we present mean data, the presence of large standard deviations indicates that there is wide range in these data and some outliers. This variation suggests ongoing work must continue to develop appropriate benchmarks, particularly for staffing among PC services in cancer centers.

This survey contributes important and timely information to the fields of oncology and PC. Consistent with the call to integrate PC into the care of patients with advanced cancer, there has been an increase in the availability of PC services, especially in hospital and clinic settings. Unfortunately, home-based services are lacking. Moreover, despite documented growth, specialty PC services in US cancer centers are still insufficient to meet demand. Moving away from fee-for-service reimbursement models to newer models that align clinical goals and financial incentives may help meet these challenges. Providing all clinicians with training in primary PC skills and investing in data collection to measure outcomes and assess value will be essential to improving the care of all patients with advanced cancer.

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