Brief Report

Changes in the Care Setting of First Consults to Palliative and Supportive Care Over a Seven-Year Period

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Abstract

Context. Optimal benefits from palliative care (PC) are achieved when first consults (PC1) occur early, in the outpatient setting. Late PC1, like those in the intensive care unit (ICU), limit these benefits.

Objectives. The objective of this study was to determine the proportion of PC1 over time in the outpatient, ICU, and inpatient non-ICU settings. We also examined patients' baseline characteristics and the timing of PC access (from PC1 to death) by the setting of PC1.

Methods. We retrospectively evaluated consecutive cancer patients' records at our cancer center to ascertain the annual number of PC1 and its distribution across settings (2011–2017). ICU PC1 ($n = 309$) and a random sample of an equal number of outpatient and inpatient non-ICU PC1 were reviewed to retrieve patients' characteristics and death date.

Results. PC1 total annual number increased by 58% from 2011 ($n = 2286$) to 2017 ($n = 3615$). We found a significant decrease in the proportion of ICU PC1 (from 2.3% in 2011 to 1% in 2017, $P < 0.001$). There were no significant changes in the proportion of PC1 at outpatient versus inpatient settings ($P = 0.2$). Hematologic cancer patients were more likely to have an ICU PC1 ($P < 0.001$). Median survival (months) was 7.7 (6.3–9.7), 3.4 (2.4–4.5), and 0.1 (0.1–0.1) for outpatient, inpatient, and ICU, respectively ($P < 0.01$).

Conclusion. PC1 total annual number has increased, and the proportion of PC1 at ICU, a very late clinical setting, is decreasing. Further efforts are needed to integrate PC in hematologic cancer care. J Pain Symptom Manage 2019;57:86–92.

Key Words

Palliative care integration, cancer care, supportive care, intensive care unit, hematological cancer

Introduction

Patients with cancer often experience severe physical, psychological, and spiritual distress that compromise their quality of life and functional status.[1,2] Their caregivers are also negatively affected by high levels of burden and psychosocial suffering.[3,4] Palliative care (PC) interventions improve cancer patients' psychological symptoms, quality of life, prognostic understanding, and, in some studies, overall survival, while also benefiting caregivers, and the health care system.[5–12] However, these positive effects vary according to the timing and setting of PC first consultations (PC1) with early outpatient referrals associated with better outcomes than those occurring late and at the inpatient setting.[8,13] Therefore, an early outpatient PC1 has been considered to be a major indicator of

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the integration of PC and oncology, whereas a late referral, generally taking place during hospitalization, is a poor PC integration marker.[14]

In the U.S., only a few cancer centers have the adequate structures, such as outpatient PC specialty clinics to promote the early integration of PC and oncology care.[15] At our comprehensive tertiary academic cancer center, we were able to build and expand the structures of the PC program over the last 20 years, allowing it, during the last decade, to have a constant growth in its clinical activity and to document the occurrence of earlier PC1.[16–19] Despite these positive prior findings, it would be important to examine the distribution and characteristics of PC1 over time and across different PC settings in more recent years. This would provide a better picture of the level of integration of PC at our institution and would be useful in identifying aspects of the integration process needing improvements. Therefore, in this study, our primary objective was to determine the relative proportion of PC1 referred to our PC team over the last seven years (2011–2017) in three clinical settings: outpatient PC clinic, intensive care unit (ICU), and inpatient non-ICU. As secondary aims, we examined the patients' demographic and clinical characteristics as well as the timing of PC access according to the setting of the PC1.

Methods

The institutional review board of the University of Texas MD Anderson Cancer Center approved this retrospective study. Informed consent was waived.

The Palliative and Supportive Care Program

At our institution, PC is provided by a team of 22 board-certified PC specialists who follow the guidelines of the National Comprehensive Cancer Network and the National Consensus Project.[20,21] All PC1 are made upon an elective request from the primary care oncologist. The PC program comprises three main structures: 1) the mobile team, which is an inpatient consultation service staffed with a PC physician, an advanced practice provider, and/or a PC fellow with access to psychologists. This service provides daily care to inpatients, including those being care at the emergency center and at the ICU[22]; 2) the Supportive Care Center is staffed with four PC specialists, eight PC-trained nurses, two social workers, two psychologists, and a pharmacist. Chaplain, dietician, and child life specialist are available based on patient's needs; 3) the acute PC unit, a 12-bed ward designed to provide care to patients and family members suffering from severe distress, while also helping with the transitioning of care, end-of-life issues, and discharge planning. This unit is also staffed with an interdisciplinary team (PC specialist, advanced practice provider, three to five PC-trained nurses, PC and/or medical oncology fellow, pharmacist, social worker, chaplain, and counselor). The decision to transfer a patient to the unit is made by the PC team based on patients' and family needs.[17]

Data Collection

To ascertain the total number of PC1 referred to the three PC settings over the last seven years (outpatient clinic, ICU, and inpatient non-ICU), we obtained information on consecutive cancer patients referred to the PC program at each study setting from September 1, 2010, through August 31, 2017. Based on the total number of PC1 at the ICU during the study time frame ($N = 309$), we took a random sample of an equal number of PC1 at the outpatient clinic and the inpatient non-ICU wards during the same period. This strategy was chosen to optimize patients' records review and data collection while still maintaining an adequate sample size. Nine hundred twenty-seven patients' electronic medical records (309 at each study setting) were then reviewed to collect patient's baseline characteristics including age, gender, ethnicity, cancer type, cancer stage (advanced or not advanced), and the timing of PC access as measured from the date of PC1 to the date of death or last contact. Advanced cancer was defined as locally advanced, recurrent, or metastatic for solid tumors and relapsed or refractory for hematologic malignancies.

Statistical Analysis

Demographics and baseline disease characteristics were summarized by descriptive statistics that include frequencies and proportions for categorical and mean ± SD and median (range) for continuous variables. The association of the setting of referral with these variables was evaluated by Kruskal-Wallis and chi-squared tests for continuous and categorical variables, respectively. The proportion of first time consults from each setting was estimated along with Clopper-Pearson (exact) CI. The confidence level for each unit was set at 98.33% to account for three simultaneous CIs (Bonferroni's approach). To evaluate the referral pattern, frequency and percentage of referrals for different settings were displayed as a function of time. We also used the Cochran-Armitage trend test (one sided) to evaluate the change in the proportion of first-time referrals at ICU versus non-ICU settings with time. The distribution of overall survival was estimated by the Kaplan-Meier method, and the log-rank test analyzed its association with the referral setting. Estimates of survival rate, median survival, and median follow-up time were calculated. $P < 0.05$ was considered statistically significant.

Results

From 2011 to 2017, a total of 19,912 PC1 occurred. The total annual number of PC1 increased by 58% from 2011 ($n = 2286$) to 2017 ($n = 3615$) (Fig. 1). During the seven-year interval, the vast majority of patients (98.5%, $n = 19{,}603$) were initially consulted either at the outpatient (48.5%, $n = 9644$) or at the inpatient non-ICU (50%, $n = 9959$) settings. A very low proportion of PC1 occurred at the ICU (1.5%, $n = 309$). Over time, we found a significant decreasing trend in the proportion of PC1 at the ICU (from 2.3% in 2011 to 1% in 2017, $P < 0.001$) versus non-ICU settings (from 97.7% in 2011 to 98% in 2017). There were no significant changes in the proportion of PC1 at the outpatient clinic versus inpatient settings ($P = 0.02$) (Table 1).

Table 2 describes the patient's demographic and clinical characteristics according to the setting of PC1. The proportion of PC1 significantly differed by age ($P < 0.01$), gender ($P = 0.016$), race ($P < 0.001$), and cancer type ($P < 0.001$) across the PC settings. Patients referred earlier as outpatients were younger than those referred to the inpatient settings, and males were more likely to be referred late, at the ICU. A higher proportion of black and Hispanic patients had their PC1 at the inpatient settings, whereas those with hematologic malignancies were more likely to have an ICU PC1.

The median time from PC1 to death or last contact was 1.9 months (95% CI 1.5–2.4) for the entire cohort. The timing of PC access was significantly different among the three settings. Patients referred at the ICU accessed PC much later: median in months, outpatient = 7.7 (95% CI 6.3–9.7); inpatient non-ICU = 3.4 (95% CI 2.4–4.5); and ICU = 0.1 (95% CI 0.1–0.1, $P < 0.01$) (Fig. 2). At the ICU, there was a significantly longer median survival over the seven-year period ($P = 0.01$). However, from 2011 through 2017, there was no statistically significant difference in the overall survival times of patients referred to the outpatient PC clinic ($P = 0.76$) or the inpatient non-ICU setting ($P = 0.09$) (Table 3).

Discussion

This retrospective study found that, during a seven-year period, there was a 58% growth in the annual number of PC1 to the PC program and that a small proportion of patients had their initial encounter at the ICU setting (1.5%). Furthermore, a significant decreasing trend was observed in referrals made at the ICU (from 2.3% in 2011 to 1% in 2017). We also found significant differences in the timing of PC access and in patient's demographic and clinical characteristics according to the setting of the PC1.

The decreasing proportion of ICU PC1 over time is an important finding of our study as the beneficial effects of PC in this setting are limited for several reasons. The frequency of delirium in these patients is very high (up to 81%), compromising patient-reported symptom assessment and communication.[13] In addition, their very short survival restricts the amount of interaction between the PC team and the patient/family after the PC1. Also, as compared to cancer patients referred at the outpatient setting, those referred at inpatient settings, such as the ICU, are at a higher risk of receiving aggressive care in the end of life.[8] At last, ICU patients miss the opportunity of receiving all the proven beneficial effects related to an early PC1 (e.g., better symptom control, improved quality of life, enhanced prognostic understanding).

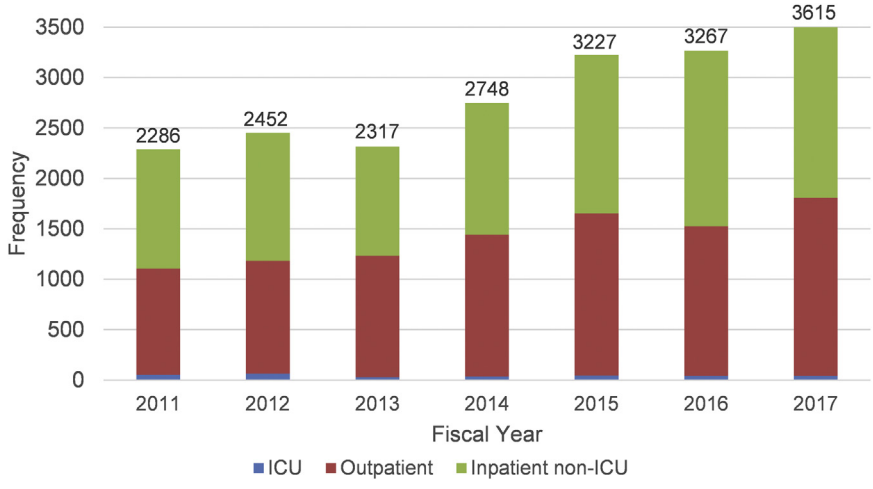

Fig. 1. Frequency of initial consults to the palliative and supportive care program at different settings over the last seven fiscal years (2011–2017). ICU = intensive care unit.

Table 1

Changes in the Proportion of First-Time Referrals to the Palliative and Supportive Care Program by Setting of Referral Over the Last Seven Fiscal Years (2011–2017)

Referral Setting	Number of Patients (%)							*P*
	FY 2011	FY 2012	FY 2013	FY 2014	FY 2015	FY 2016	FY 2017	
ICU	52 (2.3)	63 (2.6)	29 (1.3)	35 (1.3)	45 (1.4)	42 (1.3)	43 (1)	<0.0001[a]
Non-ICU								
Outpatient	1053 (46)	1120 (45.7)	1205 (52)	1408 (51.2)	1608 (49.8)	1483 (45.4)	1767 (49)	0.218[b]
Inpatient non-ICU	1181 (51.7)	1269 (51.7)	1083 (46.7)	1305 (47.5)	1574 (48.8)	1742 (53.3)	1805 (50)	
Total	2286 (100)	2452 (100)	2317 (100)	2748 (100)	3227 (100)	3267 (100)	3615 (100)	

FY = fiscal year; ICU = intensive care unit.
[a]This *P*-value indicates statistical significance (Cochran-Armitage trend test was performed to evaluate the change in the proportion of first-time referrals at ICU versus non-ICU settings over time).
[b]This *P*-value indicates no statistical significance (Cochran-Armitage trend test was performed to evaluate the change in the proportion of first-time referrals at outpatient versus inpatient settings over time).

Despite that our results showed a reduction in the proportion of PC1 at the ICU, we were not able to find a significant increasing trend in the frequency of PC1 in the outpatient setting. One possible explanation is that a longer time frame would be necessary to capture significant changes in the proportion of outpatients PC1. This hypothesis is supported by comparing the present study results with our previously published data. In the present study, from 2010 to 2017, approximately 48% of all cancer patients had their PC1 at the outpatient clinic. This percentage is higher than our prior data during an equal seven-year period (2004–2010) when the proportion of outpatients PC1 was about 33% with the remaining 67% occurring in the inpatient setting.[16] Therefore, as compared to the prior seven-year time frame, there appears to be considerable growth in outpatients PC1, indicating that over time more patients can receive the multitude of benefits of an early PC referral. Early outpatient referrals have been recognized to be one of the major indicators of the degree of integration between PC and oncology care.[14] Another potential reason for the lack of relative growth in the outpatient PC1 could be the lack of structure and processes required to cater to the high volume of referrals in such a setting. Contrary to that, the inpatient referrals are not dependent on such factors. More research is needed to understand this better.

We believe that the positive changes in the setting of PC1 and the increasing trend in the frequency of PC1 over time, especially since 2013 with peaks from 2013 to 2014 and from 2014 to 2015, are explained by a number of factors: an increased awareness among oncologists about the benefits of PC as a result of pivotal trials on the delivery of PC to cancer patients published since 2010[5,9,11,23,24]; the implementation of

Table 2

Demographic and Clinical Characteristics of Patients Referred for the First Time to the Palliative and Supportive Care Program at Different Settings: Intensive Care Unit, Inpatient Non-ICU, and Outpatient (*N* = 927)

Characteristics	Number of Patients (%)				*P*
	ICU *N* = 309	Inpatient Non-ICU *N* = 309	Outpatient *N* = 309	Total *N* = 927	
Age, yrs (IQR)	61 (21, 91)	65 (23, 94)	59 (18, 90)	62 (18, 94)	<0.01[a]
Females	151 (49)	184 (60)	156 (51)	491 (53)	0.016[a]
Race					
White	206 (67)	199 (64)	212 (70)	617 (67)	<0.001[a]
Black	37 (12)	60 (19)	37 (12)	134 (15)	
Hispanic	38 (12)	38 (12)	19 (6)	95 (10)	
Asian	16 (5)	12 (4)	17 (6)	45 (5)	
Other	9 (3)	0 (0)	18 (6)	27 (3)	
Cancer type					
Breast	45 (14)	84 (27)	85 (28)	214 (23)	<0.001[a]
Hematologic	121 (39)	67 (22)	11 (4)	199 (22)	
Thoracic	39 (13)	28 (9)	58 (19)	125 (14)	
Genitourinary	22 (7)	44 (14)	17 (6)	83 (9)	
Head & Neck	20 (7)	24 (8)	38 (12)	82 (9)	
Gastrointestinal	18 (6)	0 (0)	42 (14)	60 (7)	
Others	44 (14)	62 (20)	58 (19)	164 (18)	
Cancer stage					
Advanced[b]	289 (93)	286 (93)	286 (93)	861 (93)	0.809

ICU = intensive care unit; IQR = interquartile range.
[a]This *P*-value indicates statistical significance.
[b]Advanced cancer was defined as locally advanced, recurrent, or metastatic disease.

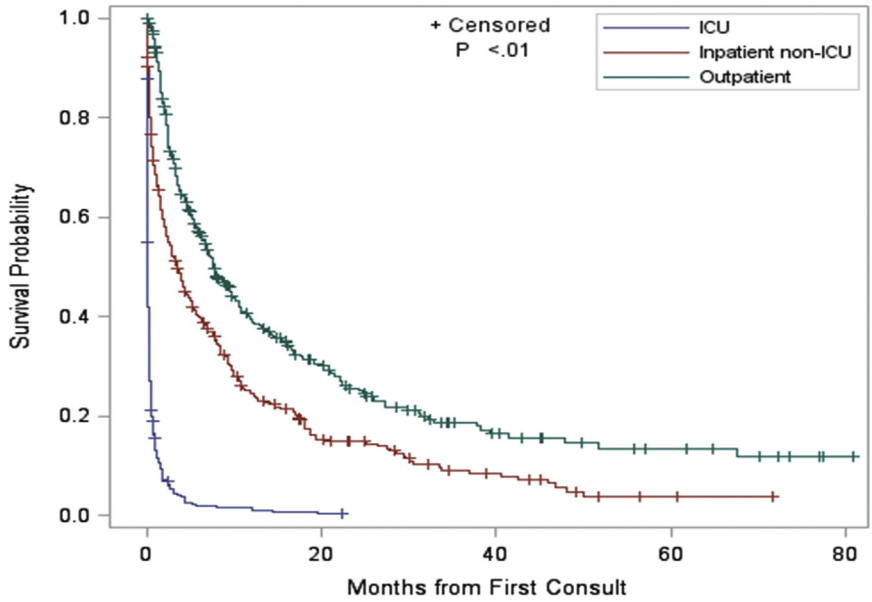

Fig. 2. Overall survival from first palliative care consultation by setting of referral. ICU = intensive care unit.

several structural and processual measures such as changing our service name from "Palliative Care" to "Supportive Care" in 2009[25]; and developing and maintaining educational/research activities involving both oncologists and PC specialists (e.g., mandatory PC rotation for oncology fellows, an annual conference on Supportive and Palliative Care for oncologists and PC specialists).[26–28]

In our cohort, the median overall survival times (measured from PC1 to death) differed significantly by the setting of referral, indicating that the place of PC1 directly reflects the time point at which cancer patients access PC services during the illness course. This finding has important implications for the clinical practice of PC. PC teams need to tailor their interventions according to the setting of patient's initial encounter. For patients referred at early clinical settings, where longitudinal care is possible to be provided, the PC team could first focus on symptom management and rapport building and then gradually work on other core PC interventions (e.g., enhancing illness understanding, discussing advanced care planning and end-of-life issues). By contrast, at very late clinical settings such as the ICU, patients' median survival is days from the PC1, and thus, the PC team may need to start discussing prognostic understanding and planning for the end of life as soon as possible.

Nevertheless, although the PC team can adapt their interventions to benefit patients and caregivers in various clinical scenarios, efforts should continue to be made to move PC1 from late to earlier clinical settings, when optimal outcomes are more likely to be achieved.[6,9–12] It is encouraging that the interval between PC1 and death at the outpatient setting is longer than at the inpatient setting. However, this also increases the number of encounters necessary per patients and might further reduce the opportunity to refer more patients to the outpatient PC clinic. More research is needed to determine the most appropriate ratio of PC encounters before death.

Patients with hematologic malignancies were much more likely to be seen at the ICU than in the other two settings. This is consistent with prior studies showing that, although hematologic cancer patients suffer from similar problems as those with solid tumors (e.g., high symptom burden and impaired quality of life), they access PC much later in the cancer course and receive more aggressive care in the end of life.[29,30] Further efforts are needed to promote

Table 3
Median Overall Survival by Year and Setting of Referral

	Median Survival (95% CI) in months							
Referral Setting	FY 2011	FY 2012	FY 2013	FY 2014	FY 2015	FY 2016	FY 2017	*P*
Outpatient	7.2 (3.4, 15.9)	4.2 (2.2, 20.2)	9.3 (6.8, 16.4)	7.2 (4.0, 13.5)	7.6 (6.3, 11.2)	6.2 (3.0, 16.7)	7.8 (4.6, 11.6)	0.76
Inpatient non-ICU	1.6 (0.6, 2.9)	1.9 (0.6, 5.4)	3.9 (1.1, 8.3)	5.2 (2.3, 7.5)	7.5 (2.8, 10.8)	6.0 (2.3, 9.8)	2.8 (1.2, 6.6)	0.09
ICU	0.1 (0.1, 0.2)	0.2 (0.1, 0.3)	0.1 (0.1, 0.7)	0.1 (0.0, 0.1)	0.1 (0.0, 0.2)	0.1 (0.0, 0.1)	0.2 (0.1, 0.3)	0.01[a]

FY = fiscal year; ICU = intensive care unit.
[a]This *P*-value indicates statistical significance.

earlier PC consultations for patients with hematologic malignancies. With regards to demographics, younger patients were more likely to be referred at the outpatient setting (earlier in the disease trajectory), whereas males were more likely to be referred at the ICU (late in the illness course). In addition, a higher proportion of black and Hispanic ethnicities had their PC1 as inpatients. Both younger age and female gender are characteristics that have been associated with higher symptom prevalence and worse symptom severity, which could justify why these patients had an earlier PC1 [1]. The ethnical differences we found may be explained by differences in cultural and religious background, knowledge about PC, and end-of-life treatment preferences.[31] More research is necessary to understand the causes of these demographic variations fully.

This study has many limitations. Its retrospective design is potentially vulnerable to data collection bias as more than one individual collected the data. It was performed in a single large academic tertiary care cancer center, where an already selected population of advanced cancer patients with complex cases and seeking clinical trials are receiving care. In addition, our PC program was created almost 20 years ago and, since then, has been able to grow and expand its services. Therefore, our findings may not apply to other types of patient population being cared for at the community or nonacademic cancer centers with different levels of PC development and resources. In addition, we did not study the reasons driving PC consults, the specific PC interventions established by the PC team, or the impact of the setting of PC1 on end-of-life quality care outcomes (e.g., hospice referral). Further studies should consider collecting this type of information to better understand differences in patient's needs, in the content of the PC interventions and patient outcomes according to the setting of referral.

In conclusion, our results indicate that the PC program is advancing its degree of integration of PC and oncology as over time the total annual number of PC1 has increased and the proportion of PC1 at the ICU, a very late clinical setting, is decreasing. Further efforts are needed to integrate PC for patients with hematologic malignancies.

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