



Association of a pediatric palliative oncology clinic on palliative care access, timing and location of care for children with cancer

Katharine E. Brock^{1,2,3} · Kristen E. Allen³ · Erin Falk⁴ · Cristina Velozzi-Averhoff⁴ · Nicholas P. DeGroot³ · Jeffrey Klick² · Karen Wasilewski-Masker^{1,3}

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Abstract

Background Most pediatric palliative care (PPC) services are inpatient consultation services and do not reach patients and families in the outpatient and home settings, where a vast majority of oncology care occurs. We explored whether an embedded pediatric palliative oncology (PPO) clinic is associated with receipt and timing of PPC and hospital days in the last 90 days of life.

Methods Oncology patients (ages 0–25) with a high-risk event (death, relapse/progression, and/or phase I/II clinical trial enrollment) between 07/01/2015 and 06/30/2018 were included. PPO clinic started July 2017. Two cohorts were defined: pre-PPO (high-risk event(s) occurring 07/01/2015–06/30/2017) and post-PPO (high-risk event(s) occurring 07/01/2017–06/30/2018). Descriptive statistics were performed; demographic, disease course, and outcomes variables across cohorts were compared.

Results A total of 426 patients were included (pre-PPO $n = 235$; post-PPO $n = 191$). Forty-seven patients with events in both pre- and post-PPO cohorts were included in the post-PPO cohort. Mean age at diagnosis was 8 years. Diagnoses were evenly distributed among solid tumors, brain tumors, and leukemia/lymphoma. Post-PPO cohort patients received PPC more often (45.6% vs. 21.3%, $p < 0.0001$), for a longer time before death than the pre-PPO cohort (median 88 vs. 32 days, $p = 0.027$), and spent fewer days hospitalized in the last 90 days of life (median 3 vs. 8 days, $p = 0.0084$).

Conclusion A limited-day, embedded PPO clinic was associated with receipt of PPC and spending more time at home in patients with cancer who had high-risk events. Continued improvements to these outcomes would be expected with additional oncology provider education and PPO personnel.

Keywords Pediatric palliative care · Pediatric oncology · Supportive care · End-of-life

Introduction

The majority of longitudinal care for pediatric oncology (PO) patients occurs in the outpatient and home settings. This is especially true for patients with progressive solid and brain

tumors, many of whom receive outpatient chemotherapy and home-based end-of-life (EOL) care [1]. While many of these patients may benefit from specialized pediatric palliative care (PPC) services, the majority of PPC programs are inpatient consultative services within academic hospital settings making it difficult to reach patients and families in the outpatient clinic or at home [2]. Whereas inpatient PPC develops a longitudinal relationship, the greatest impact of these services is likely on coping during health crises, in-the-moment care planning, medical decision making, and acute symptom control. In the lower-acuity and less stressful outpatient clinic, patients and families can more effectively contemplate and discuss their preferences for treatment, symptom management and home-based services, and discuss wishes for a worsening health state [3]. Outpatient PPC can more effectively utilize a longitudinal therapeutic alliance to enhance continuity, augment coping skills, guide advanced care planning, and ensure ongoing symptom control while also filling the gap that exists

✉ Katharine E. Brock
Katharine.brock@choa.org

¹ Department of Pediatrics, Division of Pediatric Hematology/Oncology, Emory University, Atlanta, GA, USA

² Department of Pediatrics, Division of Palliative Care, Emory University, Atlanta, GA, USA

³ Aflac Cancer and Blood Disorders Center, Children's Healthcare of Atlanta, Atlanta, GA, USA

⁴ Emory University School of Medicine, Atlanta, GA, USA

when patients have high symptom burden and/or significant psychosocial needs but are not yet enrolled in hospice care [4].

Under the umbrella of adult medical oncology, the field of palliative oncology—palliative care (PC) experts embedded into or consulting for the oncology services—has grown over the last decade, [5–10] bolstered by trials showing that patients with high-risk or incurable disease who received early PC had improved quality of life and overall survival [6–9, 11–13]. Despite practical challenges when early integrated PC models were disseminated, [14] embedded PC experts have led to earlier PC consultations, a higher number of follow-up encounters, improved EOL outcomes for patients, as well as time savings and high satisfaction rates for oncologists [9, 11, 15, 16].

Pediatric Palliative Oncology (PPO)—the integration of PPC services into routine pediatric cancer care—has been promoted by recommendations from the American Academy of Pediatrics, [17] the Psychosocial Standards of Care for Pediatric Oncology, [18] and publications about care models, hospital integration, and PPO training models [19–25]. PPO services are associated with improved symptom management, [20, 26, 27] quality of life for children and families, [28–31] as well as reduced use of health care resources, chemotherapy, and intensive care at the EOL [32–35]. In addition, bereavement outcomes improve when patients have better symptom control, receive less intensive EOL care, and families are prepared for EOL [36].

Despite increasing evidence for early PPC in children with cancer, limited resources have prevented many programs from reaching this goal [37]. U.S. children with cancer still lack consistent access to subspecialty PPC [38]. Only 60–75% of Children’s Oncology Group institutions offer PPC services—many of which are weekday, business-hour operations, and do not universally meet quality standards [2, 17, 18]. To meet the growing demand, alternative models for PPO integration have been developed [19–21, 38]. Some programs may be *embedded* within oncology while others are *freestanding*. Referrals may be *consult-based* (oncologist-identified) or *trigger-based* (e.g. all patients with metastatic solid tumor, glioblastoma multiforme). Staffing ranges from *solo-provider* models to a full *interdisciplinary team*. These programmatic differences are often based on institutional resources and culture rather than optimal patient outcomes, [19] as limited resources have forced most PPC programs to focus services on the highest risk and most complex patients who are refractory to management strategies from the primary team. Currently, there are no validated measures to identify high-risk events warranting subspecialty PPC in pediatric oncology patients. Retrospective studies often included only deceased patients, although other high-risk events such as relapse, disease progression, and/or early phase (I/II) clinical trial enrollment could also be used to identify additional patients appropriate for PPC consultation [1, 35].

In this manuscript, we assess whether an embedded, consultative, limited-day, solo-PPC specialist provider outpatient clinic is associated with changes in access to PPC, timing of PPC consultation relative to time of death, and the amount of time spent out of the hospital in the last 90 days of life for pediatric oncology patients with high-risk events. We hypothesized that access to this model of PPO program would be associated with increased access, earlier timing of PPC consultation among children with cancer, and more days spent at home in the last 90 days of life.

Methods

Clinical setting

Children’s Healthcare of Atlanta (CHOA) is a large, free-standing pediatric healthcare system. The Aflac Cancer & Blood Disorders Center at CHOA receives nearly 480 new patients with cancer annually. Inpatient PPC consultative services started for all inpatients in October 2011. On July 1, 2017, an outpatient, embedded, consult-based PPO clinic (“Supportive Care Clinic”) became available for children, adolescents, and young adults with cancer. Clinic metrics were previously published. [19] Due to resource limitations, PPO clinic was limited to one-half day (capacity for four encounters) per week for 3 months, then increased to two half-days per week (capacity for eight encounters). If capacity was exceeded, priority was given to patients with acute pain, high complexity, or those with the shortest survival time. Clinic was staffed by one physician board certified in Pediatric Oncology and Hospice and Palliative Medicine. Due to oncologist preference, PPO clinic referrals were made by the patient’s oncology team at their discretion without specific designated triggers for referral (e.g., bone marrow transplant, relapsed solid tumor). Patients receiving PPO clinic consultation also received inpatient PPC during hospital admissions based on their current needs. Patients who initially received PPC were eligible to receive PPO clinic services, but may not have due to dying while inpatient, discharging to hospice, lacking clinic follow-up, or inability to coordinate oncology and PPO appointments. Oncology resources (scheduling, case management, social work, child life, nursing) were utilized for clinic; there were no additional PPC interdisciplinary team members.

Inclusion criteria for retrospective analysis

Patients with (1) cancer (2) between the ages of 0 and 25 years at diagnosis who were (3) treated at the Aflac Cancer & Blood Disorders Center and who (4) experienced at least one high-risk event between July 1, 2015 and June 30, 2018 were included in the dataset for further data collection and analysis.

High-risk events were defined a priori as death, relapse, disease progression, and/or early phase (I/II) clinical trial enrollment. This population was chosen in order to focus the research on the most at-risk patients as it was clear, even prior to starting clinic, that PPC services could not be achieved for all patients with cancer. This study was granted expedited approval by Emory University and CHOA Institutional Review Boards; consent was not required due to the retrospective nature.

Data collection

Patients who had a high-risk event (death, relapse, or disease progression) between 7/1/2015 and 6/30/2018 were queried from the CHOA/Georgia cancer registry, maintained by the Clinical Research Office. A list of patients enrolled in a phase I/II clinical trial during the specified time was obtained from the CHOA Developmental Therapeutics research team. This cumulative list directed electronic medical record abstraction (E.F or C.V-A). Duplicate entries were removed. Variables abstracted include demographic information (age at diagnosis, age at death, sex, gender, race, ethnicity, language, diagnosis/treatment campus), disease-based information (diagnosis, date of diagnosis, disease progression/relapse status, and phase I/II trial enrollment), and PPC course (PPC consultation status, date of first consultation, total number of PPC clinic and inpatient encounters within the allotted study period, hospice enrollment, and location of death). Second author (K.E.B) chart review was available. PPC involvement was defined from the patient's view—receipt of inpatient PPC, PPO clinic, or both. “Late” PPC involvement was defined as PPC consultation occurring \leq 30 days prior to death [34]. Number of days admitted to the hospital in the last 90 days of life was obtained from hospital administrative data.

Pre-PPO and post-PPO cohorts

From the identified patients, two cohorts were established based on whether patients had access to the PPO clinic intervention. The *pre-PPO cohort* was defined as patients with a high-risk event occurring between July 1, 2015 and June 30, 2017. These patients could be referred for PPC services during inpatient encounters but did not have access to the PPO clinic. The *post-PPO cohort* included (1) patients with a high-risk event between July 1, 2017 and June 30, 2018 and (2) those alive at the end of the pre-PPO cohort who subsequently had another high-risk event during the post-PPO time frame. These patients had access to both inpatient PPC services and PPO clinic.

Statistical analysis

Descriptive statistics were carried out on study variables, using mean and standard deviation (SD) or median and interquartile range (IQR). *t* test/Mann-Whitney *U* test and Chi-square test/Fisher's exact test were used to explore differences in demographic, patient disease course, and outcome variables between the pre- and post-PPO cohorts. Sensitivity analysis was performed removing all 47 patients ($n = 379$) who appeared in the pre- and post-cohort. Multinomial logistic regression was used to explore the effect of early versus late consultation time, time from PPC consultation to death (days), and pre- versus post-cohort on the location of death. *P* values were two-sided and considered statistically significant if $p < 0.05$. SAS Enterprise Guide 7.1 (Cary, NC) was used for all analyses.

Results

There were 426 unique patients with a high-risk event included in the study. No patients were excluded. The pre-PPO cohort included 235 patients and the post-PPO cohort included 191 patients. The most common diagnoses included solid tumors (36.4%, 155/426) and brain tumors (35.0%, 149/426), followed by leukemia/lymphoma (28.6%, 122/426). The average age at diagnosis was 8.4 years (SD = 5.9) with 31.2% of patients being non-Hispanic black. There were no significant differences in baseline demographic factors between the pre-PPO and post-PPO cohort (Table 1).

A higher proportion of post-PPO patients received PPC consultation (45.6%, 87/191) compared with the pre-PPO cohort (21.3%, 50/235, $p \leq 0.0001$). The consultation locations were PPO clinic (38/87, 43.7%) and inpatient (49/87, 56.3%). PPO clinic followed 59.2% (29/49) of patients first seen inpatient. Of the 20/49 not seen in PPO clinic, 13 died during that hospitalization or after a discharge to hospice. In total, 77.0% (67/87) of post-PPO patients who received PPC were seen in PPO clinic. The median number of PPC encounters did not differ significantly between the cohorts (pre-PPO cohort = 8 [IQR = 3,21]; post-PPO cohort = 6 [IQR = 2,16]; $p = 0.5135$). The median time from diagnosis to death was unchanged (527 days in the pre-PPO cohort; 573 days in the post-PPO cohort, $p = 0.3284$). Early-phase (I/II) clinical trial enrollment was similar across cohorts (Table 2).

Several analyses occurred in deceased patients only ($n = 213$). More patients from the pre-PPO cohort were deceased (60.4%, 142/235) than the post-PPO cohort (37.2%, 71/191, $p < 0.0001$) (Table 2). The median time from PPC consultation to death was significantly longer for those in the post-PPO cohort (pre-PPO cohort = 32 days [IQR = 6, 105]; post-PPO cohort = 88 days [IQR = 30, 132]; $p = 0.027$), a 275% increase in days of PPC involvement (Table 2). The

Table 1 Characteristics of pediatric cancer patients experiencing a high-risk event, 2015–2018

	N (%)			p value ^b
	Full cohort, 2015–2018 (N = 426)	Pre-PPO cohort, 2015–2017 (N = 235)	Post-PPO cohort, 2017–2018 (N = 191) ^a	
Age at diagnosis, years [mean (SD)]	8.4 (5.9)	8.1 (5.7)	8.7 (6.2)	0.2278
Age at death, years [mean (SD)]	11.8 (6.6)	11.5 (6.4)	12.4 (7.0)	0.1868
Sex				
Female	205 (48.1)	117 (49.8)	88 (46.1)	0.4455
Male	221 (51.9)	118 (50.2)	103 (53.9)	
Ethnicity/race				
Non-Hispanic, White	209 (49.1)	115 (48.9)	94 (49.2)	0.7635
Non-Hispanic, Black	133 (31.2)	71 (30.2)	62 (32.5)	
Non-Hispanic, Asian/declined	18 (4.2)	12 (5.1)	6 (3.1)	
Hispanic, any race	66 (15.5)	37 (15.7)	29 (15.2)	
Diagnosis type				
Leukemia/lymphoma	122 (28.6)	68 (28.9)	54 (28.3)	0.9025
Solid tumor	155 (36.4)	87 (37.0)	68 (35.6)	
Brain tumor	149 (35.0)	80 (34.0)	69 (36.1)	

PPO pediatric palliative oncology, SD standard deviation

^a Post-PPO cohort includes 144 new patients (high-risk event occurring in 2017–2018) and 47 patients that had a high-risk event in both the pre- and post-PPO cohort (were alive to receive the PPO clinic intervention)

^b Pre-PPO cohort vs. post-PPO cohort

proportion of deceased patients receiving early PPC consultation (greater than 30 days from death) increased from 50.0% to 71.8% ($p = 0.04$) (Fig. 1). Of the 28 early consultations, 67.8% (19/28) occurred inpatient; the PPO physician completed 31.6% (6/19), and 31.6% (6/19) received EOL care in the hospital or via home hospice. Despite stable rates of hospice enrollment across the cohorts, patients in the post-PPO cohort had fewer inpatient days in the last 90 days of life (pre-PPO cohort = 8 days [IQR = 0.35]; post-PPO cohort = 3 days [IQR = 0.18], $p = 0.0084$) (Table 2). When controlling for cohort, patients who received early PC consultation were 30.2% less likely to die in the hospital, although this was not statistically significant (odds ratio, OR = 0.691; 95% CI: 0.32, 1.53; $p = 0.3522$). Analyses and p values were unchanged in a sensitivity analysis removing the 47 patients who had high-risk events in both cohorts except for “days from PPC consultation to death,” while the absolute values were relatively unchanged (pre-PPO cohort = 32 days, post-PPO cohort 80 days), patients were differentially removed from the post-PPO cohort, reducing power ($p = 0.096$).

In the pre-cohort, 46 patients died who had received a PPC consultation. Only 8/46 (17.4%) died at home; of those, 6/8 (75%) had experienced early PPC consultation. Of the 33/46 (71.7%) patients who died in the hospital, only 14/33 (42.4%) experienced early PPC consultation. In the post-cohort, 39 patients died who had received a PPC consultation. An increased number, 15/39 (38.5%) died at home, and of those, 12/15 (80%) had received early PPC consultation. An additional 18 patients died in the hospital, and of those, 12/18 (66.7%) had received early PPC consultation (Fig. 2). The post-cohort was 71.1% less likely to die in the hospital compared with the pre-cohort, controlling for early versus late consultation time (OR = 0.289; 95% CI 0.14, 0.61; $p = 0.001$).

Discussion

This study suggests that the addition of a limited day, solo provider, embedded PPO clinic within an academic PO program is associated with receipt of PPC services, earlier timing of PPC interventions relative to time of death, decreased days in the hospital at the EOL, and improved compliance with psychosocial standards for early, integrated PPC within pediatric cancer care [18, 39]. However, this limited intervention does not serve all patients who could benefit from PPC, as only 45.6% of post-PPO cohort patients with high-risk events received PPC services despite a 24% absolute increase in consult volume and a decrease in the rate of late consultation (within 30 days of death) from 50% to 28%.

Integrating any new clinical service into an established practice requires changes in the existing provider’s behavior. When implemented within a large PO group, this requires “culture change” and overcoming barriers [40]. For example, although oncologists occasionally are concerned that increased PPC involvement can detract from curative-intent therapy, the increased PPC consultation rate did not correlate with decreased phase I/II enrollment or survival time [40]. Importantly, all patients referred to PPC in this cohort required that a PO clinician request consultation from subspecialty PPC. While culture change is multi-factorial, it is partially measured by changes in consult rate and the proportion of patients receiving early consultation. In this early-stage clinic, inpatient and outpatient PPC consultation rates were combined as the receipt of PPC services was more important than the location of the consultation. Furthermore, any embedded PPO clinic incorporates education and training for PO staff that also facilitates culture change.

Few programs have ensured early integration of specialty PPC services for all PO patients and this was not a realistic goal for the PPO clinic [41, 42]. In a resource-limited environment, it is not practical nor appropriate for all PPC needs to be addressed by PPC specialists; PO teams must be supported in addressing the less complex, less refractory challenges

Table 2 Outcomes among pediatric cancer patients experiencing a high-risk event by cohort, 2015–2018

	<i>N</i> (%)		<i>p</i> value ^c
	Pre-PPO cohort 2015–2017 (<i>N</i> = 235)	Post-PPO cohort 2017–2018 (<i>N</i> = 191)	
Vital status			
Deceased	142 (60.4)	71 (37.2)	< 0.0001
Alive	93 (39.6)	120 (62.8)	
Phase I/II enrollment			
No	181 (77.0)	135 (70.7)	0.1370
Yes	54 (23.0)	56 (29.3)	
Received palliative care			
No	185 (78.7)	104 (54.5)	< 0.0001
Yes	50 (21.3)	87 (45.6)	
Received hospice^a			
	<i>n</i> = 142	<i>n</i> = 71	
No	73 (51.4)	34 (47.9)	0.6280
Yes	69 (48.6)	37 (52.1)	
Median (IQR)			
	2015–2017 (<i>N</i> = 235)	2017–2018 (<i>N</i> = 191)	<i>p</i> value ^c
Number of palliative care encounters (inpatient and outpatient)			
	<i>n</i> = 50	<i>n</i> = 85	0.5135
	8 (3, 21)	6 (2, 16)	
Time from first palliative care consult to death, days			
	<i>n</i> = 46	<i>n</i> = 39	0.0270
	32 (6, 105)	88 (30, 132)	
Time from diagnosis to death, days			
	<i>n</i> = 141 ^b	<i>n</i> = 71	0.3284
	527 (276, 1110)	573 (315, 1290)	
Number of inpatient days in the last 90 days of life			
	<i>n</i> = 14 ^b	<i>n</i> = 71	0.0084
	8 (0, 35)	3 (0, 18)	

^a Among the 142 and 72 deceased patients in the pre-PPO and post-PPO cohort, respectively

^b Unable to determine date of death for *n* = 1 deceased patient

^c Pre-PPO cohort (2015–2017) vs. post-PPO cohort (2017–2018)

IQR interquartile range, *PPO* pediatric palliative oncology

through education, training, and support from PPC specialists. When a PPO program becomes available, consultation rates and timing can be influenced in multiple ways. First, culture plays a major role in the acceptance and utilization of services. Utilizing a physician board-certified in both oncology and PPC impacted some barriers to consultation. Second, PPO clinic provided additional settings and times for patient encounters, notably for those patients likely to be missed in an inpatient-only model. For example, in comparison with bone marrow transplant patients who are often captured during their inpatient hospitalization, patients with brain and solid tumors often receive oral or other outpatient therapies and services may better align in the outpatient clinic. Third, PPO clinicians participate in PO multi-disciplinary team meetings and informal interactions in shared clinic spaces, providing PPO clinicians additional teaching opportunities critical to improving the PO team's primary PPC skills. Finally, naming the clinic "supportive" instead of "palliative" care reduces barriers to consultation by distancing services from EOL care [6].

There are inherent differences in discussing advance care planning in an inpatient and outpatient setting including the sense of immediacy in medical decision making. In the outpatient setting, clinicians can help families plan for a poorer health state and provide anticipatory guidance before the situation worsens. Talking about a family's wishes for when their child is sicker and planning for the EOL make the desired plan of care more likely [43, 44]. In this study, a shift in the setting of care was observed with more patients spending additional days at home in the last 90 days of life, a common preference of children and families reported in other studies [43]. Additionally, being in the post-PPO cohort and early PPC consultation were important factors in achieving a home death. This shift was likely impacted by the PPO physician managing symptoms in the clinic and home, ensuring appropriate equipment was available, as well as preventing admissions to the hospital if a child, teen, and family wished to remain at home.

As CHOA cares for most of Georgia's children with cancer, this is a representative statewide sample inclusive of all

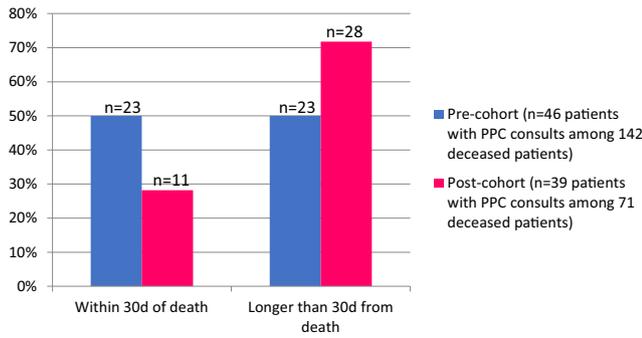


Fig. 1 Frequency of PPC consultation occurring early (≤ 30 days) versus late (> 30 days from death). PPC consultations among deceased patients only. Early vs. late PPC consultation among pre- and post-cohorts, $p = 0.0410$. Abbreviations: PPC, pediatric palliative care

cancer types. The patients represent a diverse patient base including half of the population being Hispanic, Black, or Asian/other. A large sample size was accrued in 3 years, increasing the validity of the study. In systems with limited resources, PPC programs often focus services to the highest-risk patients but identifying these patients can be difficult. Utilizing high-risk events as a trigger for referral may represent an innovative tool for research and clinical purposes [45].

Limitations of this single institution study include the differential time across cohorts—2 years in the pre-PPO group compared with 1 year in the post-PPO group allowing the pre-PPO cohort a longer time frame to accrue PPC encounters. In addition, a typical PPC intervention for the pre-PPO cohort included daily encounters from the inpatient service. While these encounters continued in the post-PPO cohort, the additional encounters from the PPO clinic intervention occurred

less frequently (weekly/monthly). These factors, in combination with resource limitations on the PPO clinic and a high percentage of referrals occurring in last months of life, could account for the lack of change in absolute number of PPC encounters across the pre- and post-PPO cohorts.

In this dataset, the cumulative number and timing of high-risk events prior to death were not available. However, as many patients carried a poor prognosis, it is likely that a number of patients experienced relapse/progression, phase I/II enrollment, and/or death soon after the end of data collection. This would result in underestimating PPC consultation and hospice enrollment rates. Given the different accrual time for the groups, this may have differentially affected the post-PPO group. While other studies suggest a preference for death at home, it is uncertain whether days spent in the hospital aligned with patient and family preferences, as the location of EOL care and death preference was not reliably documented in the medical record [43, 44]. Finally, this study did not measure the potential challenges inherent in a solo-provider PPO clinic including need for additional interdisciplinary staff, the required non-billable or care-coordination time, or the impact of providing support to PO providers when caring for patients with serious illness. Providing this type of care may be challenging for the solo provider, and the impact on sustainability, burnout risk, and moral injury needs to be better understood.

Future studies should consider whether embedded models are clinically efficacious for patients, families, and oncologists, cost-effective for health care systems, and sustainable for PPC specialists. Studies will need to be expanded to all children with poor prognosis cancers, and, in more resource-

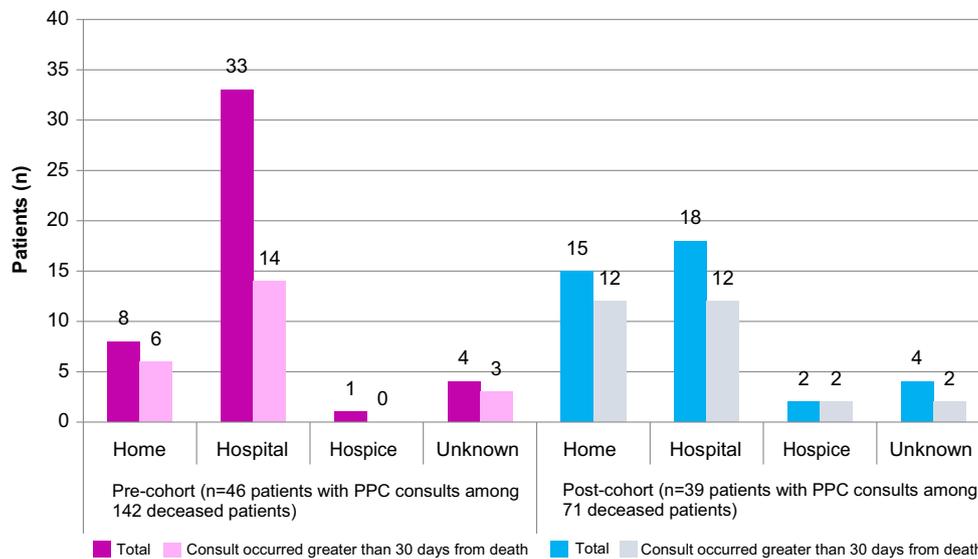


Fig. 2 Location of death for those with PPC consultation and relation to early (> 30 days) vs late (≤ 30 days before death) PPC consultation. * Post-cohort 71.1% less likely to die in the hospital versus at home compared with the pre-cohort, controlling for early versus late consultation time (OR = 0.289; 95% CI 0.14, 0.61; $p = 0.0011$). When controlling for

pre- versus post-cohort, patients who received an early (> 30 days prior to death) PC consultation were 30.2% less likely to die in the hospital, although this was not statistically significant (OR = 0.698; 95% CI: 0.32, 1.53; $p = 0.3679$). Abbreviations: PPC, pediatric palliative care

rich environments, all cancers. Data collection should include additional clinically oriented outcomes including the impact on quality of life, coping, mental health, EOL, and overall survival utilizing patient-reported outcomes whenever possible. Additional studies are warranted to determine which patients most benefit from specialized PPC, how to identify these patients prospectively, and how to best reach those patients regardless of demographics or oncologist. Electronic health system alerts could be applied to pediatric oncology as they may provide improved sensitivity in patient selection. The effect of PPO clinics on PO and PPC team members should be assessed by evaluating clinic feasibility, acceptability, provider comfort, competence and PPC knowledge, time savings, job structure and satisfaction, burnout, and compassion fatigue. With improved clinical resources and a more robust evidence base, the impact of a PPO clinic could ultimately lead to similar patient-centered care outcomes as adult oncology centers and highly resourced pediatric cancer referral centers.

Conclusion

The initiation of a limited-day, solo-provider, consult-based, embedded PPO clinic for children with cancer and a high-risk event was associated with increased PPC consultation, earlier receipt of PPC services relative to the time of death, and more time at home in the last 90 days of life. Despite the significance of these findings, there was still substantial room for improvement. Only 46% of PO patients with high-risk events received subspecialty PPC—usually in the last 3 months of life—likely due to evolving culture change within PO and limited availability of the PPO clinic. Continued improvements to these outcome measures would be expected with expansion of the PPO clinic, developing triggers for consultation, and continued PO provider education. Cancer centers and pediatric health care systems should consider an outpatient PPO model to deliver patient-centered care that helps meet the standards of care outlined in the Psychosocial Standard for Palliative Care in Pediatric Oncology. Such a model has potential to improve symptom management and quality of life while decreasing health care cost at end-of-life.

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Authors’ contributions Study conception and design were performed by Katharine Brock and Karen Wasilewski-Masker. Material preparation and data collection were performed by Katharine Brock, Kristen Allen, Erin Falk, and Cristina Velozzi-Averhoff. Data analysis was performed by Katharine Brock and Kristen Allen. The first draft of the manuscript

was written by Katharine Brock and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data availability Deidentified individual participant data (including data dictionaries) will be made available. Data will be made available upon publication to researchers who provide a methodologically sound proposal for use in achieving the goals of the approved proposal. Proposals should be submitted to Katharine.brock@choa.org.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethics approval This retrospective chart review study involving human participants was in accordance with the ethical standards of the institutional and national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The Human Investigation Committee (IRB) of Emory University approved this study.

Consent to participate Not applicable.

Consent to publish Not applicable.

Code availability The statistical analysis plan will be made available to researchers who provide a methodologically sound proposal for use in achieving the goals of the approved proposal. Proposals should be submitted to Katharine.brock@choa.org.

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