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Abstract

Background: Children with relapsed/refractory cancer have a myriad of palliative care needs. While pediatric oncology clinicians meet many of these needs, studies suggest that these children often have distressing symptoms and that families feel unprepared for their child's end-of-life (EOL). Oncology clinicians cite barriers to pediatric palliative care (PPC) consultation, including concerns that PPC teams will upset families with EOL discussions. This study evaluated topics addressed by PPC teams over the course of their relationship with children who died from cancer. **Methods:** Retrospective chart review of children who were diagnosed with relapsed/refractory cancer, received PPC consultation at an academic children's hospital, and died between January 2008 and January 2017. Information was extracted regarding the child's treatment, EOL care, and the content of PPC consultation over the course of the team's relationship with the child/family. **Results:** Fifty-six children were included in the analysis. The most frequent reasons for the initial consult were pain ($n = 31$, 55%) and non-pain symptom management ($n = 18$, 32%). At the initial consult, the PPC team most often discussed symptom management and psychosocial support. Prognosis was not discussed in any initial consult. Over subsequent visits, the PPC team expanded their scope of discussion to include goals of care, advance care planning, and hospice. **Discussion:** Concerns from oncology clinicians that PPC teams will extend beyond the reasons for initial consult into prognostic/EOL discussions at the first visit may be unfounded. Greater familiarity with PPC team practices may facilitate more timely consultation of PPC and its complementary set of services.

Keywords

palliative care, end-of-life, pediatric oncology

Approximately 2,500 children, adolescents, and young adults die from relapsed/refractory cancer each year in the United States (Murphy et al., 2021). Children with relapsed or refractory cancer often have distressing symptoms including pain, fatigue, nausea, dyspnea, and anxiety at end-of-life (EOL; Wolfe et al., 2000). Existing data suggests that many of these children and families also experience distress related to outstanding psychological, spiritual, existential, and care coordination needs (Comas Carbonell et al., 2021; Vern-Gross et al., 2015). Addressing these needs is critical to improving EOL care for these patients and families.

Pediatric oncology clinicians, including nurses, physicians, and psychosocial professionals, strive to provide high-quality comprehensive cancer care for their patients. These multidisciplinary team members have experience

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addressing many primary palliative care needs of patients and families including providing symptom management, supporting adaptation to illness, and attending to emotional needs. These clinicians also guide families through life-changing medical decisions and support them when treatments fail.

In addition to the strong primary palliative care skills and practices provided by pediatric oncology clinicians, children and families benefit from specialty pediatric palliative care (PPC). As defined by the National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care (2018), PPC teams have specialty training in the core domains of palliative care provision, including physical, psychological, social, spiritual, religious, and existential care of people and families facing serious illness. This expertise also extends to care during the acute dying process and bereavement care, as well as ethical and legal aspects of care (Ferrell et al., 2018). PPC team consultation among children with cancer has been shown to reduce symptom-specific suffering (Marcus et al., 2020; Wolfe et al., 2008) and improve child quality of life (Friedrichsdorf et al., 2015). It has also been associated with less intensive EOL care including fewer procedures in the last month of life, less cardiopulmonary resuscitation, and fewer deaths in the hospital or intensive care unit (Kaye et al., 2020; Snaman et al., 2017; Ullrich et al., 2016).

Despite the expertise of PPC clinicians and calls for the incorporation of PPC as the standard of care for all children with cancer (American Academy of Pediatrics, 2000; Ferrell et al., 2017; Weaver et al., 2015), pediatric oncology clinicians have expressed concerns regarding the involvement of PPC teams in the care of their patients (Davies et al., 2008). Clinicians may have concerns that PPC consultation will lead to fragmented communication, generate conflict between families and clinicians, and upset parents who may not be ready to discuss their child's incurable disease (Bogetz et al., 2019; Szymczak et al., 2018). Oncology clinicians may avoid consultation out of a strong sense of responsibility for their patients and conflicting feelings about sharing this responsibility with other clinicians. Furthermore, they may worry that families will feel burdened by added clinicians (Dalberg et al., 2018) or alienated by their oncology team (Szymczak et al., 2018). The closed team approach may limit the integration of PPC into routine oncology care, as these clinicians often serve as gatekeepers to specialist services. Additionally, delayed PPC consultation may perpetuate misconceptions that palliative care is only provided at EOL and that it equates to hospice care. Despite these perceptions, evidence indicates that families are rarely opposed to early PPC consultation (Levine et al., 2017). Furthermore, some families receiving care from PPC teams report improved communication and family relationships (Hancock et al., 2018; Kassam et al.,

2015) and decreased caregiver burden (Chong et al., 2018; Groh et al., 2013). Despite many opportunities for consultation (Labudde et al., 2021) and evidence of PPC benefits, persistent barriers to integration of PPC raises the concern that misconceptions regarding PPC involvement may prevent children and families from receiving PPC services.

Given the nature of consultative etiquette, PPC teams should aspire to be transparent about the content of consultations and the services offered to patients/families and oncology teams. Despite the need for a clear understanding of PPC team consultation practices, there is limited literature examining PPC team interactions with children and families over time. This study aimed to describe the evolution of discussion topics with individual children facing relapsed/refractory cancer and their families from the time of initial PPC consultation until death.

Methods

This study reports findings from a larger retrospective cohort study examining EOL characteristics among children ages 0 to 25 years who died from relapsed/refractory cancer between January 2008 and January 2017 at an urban tertiary academic children's hospital. Deceased children were identified from a comprehensive bereavement database kept by the organization which included patients that died in hospital, at other facilities, or home. Deaths were reviewed starting in 2008 because this was the time after which electronic medical records were available. This study was reviewed and was determined to be non-human subjects research by the University of California San Francisco Institutional Review Board.

The multidisciplinary team of researchers (MR, JK, JB) developed a case report form based on similar studies examining EOL characteristics in children receiving bone marrow transplants (Ullrich et al., 2010, 2016). The case report form was housed in REDCap, a secure web platform for building and managing online databases and surveys (Harris et al., 2009, 2019). The form included (a) basic demographic information; (b) age at diagnosis; (c) stem cell transplant status; (d) medical interventions in the last 12 months of life; and (e) the child's mode and location of death. Children were considered to have received PPC consultation if there was at least one initial consult note in the chart from the PPC team. Data regarding the consultative relationship were extracted including (a) age at initial PPC consult and death; (b) reason for consultation; and (c) number of subsequent palliative care follow-up visits. A priori topics covered by PPC teams were also included in the case report form based on the NCP Clinical Practice Guidelines for Quality Palliative Care (2018) and existing studies examining the content of palliative care consultations (Marcus et al., 2018). These included a total of 11 topic areas

covering symptom management, care coordination, advance care planning, spiritual, and psychosocial support. Two distinct data fields on the case report form distinguished topics covered (a) in the initial consult or (b) during any subsequent visit with the PPC team. Topics were not mutually exclusive, and all the topics documented as discussed by the PPC team were recorded.

Electronic medical records were reviewed manually by three study members (MR, JK, JB) who extracted relevant data and entered it into the corresponding fields in REDCap. Questions or disputes about data from the electronic medical record were reviewed as a group during monthly multidisciplinary study team meetings where any confusing or missing data were presented and then the chart was reviewed as a team (MR, JK, JB). Once data collection into REDCap was complete, the study team reviewed the data to clean it and to confirm any outliers with an additional manual review of the chart. All identifying information was removed prior to univariate analysis which examined means, medians, and ranges.

Results

Sample Characteristics

A total of 56 patients were included and represent consecutive deaths among children, adolescents, and young adults with relapsed/refractory cancer who received PPC consultation (Table 1). Approximately 43% were female ($n=24$) and were initially diagnosed with cancer at a median age of 12 years (IQR 5, 16). Half identified as non-Hispanic/Latino Caucasian ($n=28$, 50%) and 18% ($n=10$) were Hispanic/Latino. The children predominantly had hematologic malignancies ($n=15$, 27%), brain tumors ($n=11$, 20%), and neuroblastoma ($n=6$, 11%). More than one-third ($n=20$, 36%) received a stem cell transplant in the course of their therapy for diagnoses such as hematologic malignancies ($n=13$, 65%), neuroblastoma ($n=2$, 10%), or brain tumors ($n=1$, 5%).

In the 12 months prior to death, children had a median of four (IQR 2, 5) hospitalizations and two surgeries/invasive procedures (IQR 1, 3). Children died a median of 615 days after their initial primary oncologic diagnosis (IQR 324, 1225). Location of death included non-ICU hospital setting for 38% ($n=21$) of children, while 34% ($n=19$) died at home, and 18% ($n=10$) died in an ICU setting (location unknown for three patients). While the majority of children died while receiving comfort directed care ($n=39$, 70%), one child died after active resuscitation (2%), and 15 (27%) died after withdrawal or withholding of interventions. Hospice or home-based palliative care was involved with 50% ($n=28$) of families, while 46% ($n=26$) had no home hospice or home-based palliative care supports.

PPC Consultation

The reasons for PPC consultation were not mutually exclusive. The most frequent reasons for consultation from the primary team were pain management ($n=31$, 55%), non-pain symptom management ($n=18$, 32%), and goals of care/decision-making ($n=9$, 16%). Other reasons for consult that occurred less often included coordination of care/home care/hospice, psychosocial support, withdrawal or withholding of interventions/EOL care, and advance care planning. No consults were initiated for the topic categories of child/family quality-of-life, spiritual support, or prognostic discussions. Children received PPC consultation a median of 532 days (range 29–3,452; IQR 242, 988) after their primary oncologic diagnosis, which was a median of 68 days (range 1–1,150; IQR 23, 154) prior to their death (Table 2).

The PPC team had a median of nine subsequent visits with each patient and family after the initial consult (range 0–153; IQR 2, 20). There were seven children and families (13%) who were only seen once by the PPC team and an additional nine (16%) who were seen ≤ 3 times. These patients and families who received three or fewer visits from the PPC team made up all of the referrals for advance care planning, withdrawal or withholding of interventions/EOL care, and child life/ancillary services for keepsakes.

The majority of initial visits with the PPC team included discussion of pain management ($n=48$, 86%), non-pain symptom management ($n=28$, 50%), and psychosocial support ($n=22$, 39%) (Table 2). The PPC team did not discuss prognosis with patients and families in any of the 56 initial consult visits. Even when consulted for withdrawal/withholding of interventions/EOL care, the PPC team only addressed this at the first visit for one of the three patients. On occasion, the PPC team expanded upon the reason(s) for consult in their initial visit to include topics such as the child and family's quality of life, care coordination/home care/hospice, and goals of care/decision-making.

In contrast, in subsequent follow-up visits, the PPC team covered a wide variety of palliative care topics (Table 2). Over the course of subsequent visits, the majority of patients/families had a discussion with the PPC team about pain ($n=44$, 79%) and non-pain symptom management ($n=42$, 75%). For nearly half of the patients/families, topics such as care coordination/home care/hospice, goals of care/decision-making, psychosocial support, or advance care planning were discussed at a subsequent visit. The PPC team covered topics including spiritual support ($n=12$, 21%), child life/ancillary services ($n=13$, 23%), and prognosis ($n=14$, 25%) (Figure 1). In general, the more subsequent visits with the PPC team, the more topics were covered.

Discussion

In this study of PPC consultation practices among children with relapsed/refractory cancer and their families,

Table 1. Child Demographics (N = 56)

Characteristics	n	%	Mdn	IQR
Gender female	24	43		
Race and ethnicity ^a				
Caucasian, not Hispanic or Latino	28	50		
Hispanic or Latino	10	18		
Asian or Pacific Islander	8	14		
Black or African American	3	5		
Caucasian, Hispanic or Latino	2	4		
Native American	1	2		
Other	4	7		
Primary diagnosis and transplant status				
Median age at diagnosis, years ^b			12	5, 16
Primary diagnosis				
Hematologic	15	27		
Brain tumor	11	20		
Neuroblastoma	6	11		
Rhabdomyosarcoma	4	7		
Ewing's sarcoma	2	4		
Hodgkin's lymphoma	1	2		
All other oncologic diagnoses not listed above	17	30		
Received stem cell transplant	20	36		
Reason for stem cell transplant				
Hematologic	13	65		
Neuroblastoma	2	10		
Brain tumor	1	5		
Other	4	20		
Care in the last 12 months of life				
Number of ICU admissions			1	0, 1
Number of hospitalizations			4	2, 5
Number of surgeries/invasive procedures			2	1, 3
Advance care planning discussion				
Documented ACP discussion ^c	4	7		
Timing of discussion in days prior to death			26	12, 80
POLST completed ^c	32	59		
EOL characteristics				
Median age at death, years			14	8, 21
Median duration of survival after diagnosis, days			615	324, 1225
Median duration of survival after stem cell transplant, days			249	126, 506
Location of death				
Non-ICU, Hospital	21	38		
Home	19	34		
ICU, Hospital	10	18		
Hospice house/facility	3	5		
Unknown	3	5		
EOL home supports				
Hospice involvement	26	46		
Home-based palliative care involvement	2	4		
None	26	46		
Unknown	2	4		
Mode of death ^a				
Active resuscitation	1	2		
Withdrawal or with-holding of interventions	15	27		
Comfort	39	70		
Unknown	3	5		

Note. ICU = intensive care unit; IQR = interquartile range; ACP = advance care planning; POLST = physician orders for life-sustaining treatment; EOL = end-of-life.

^aMultiple selections allowed

^bSample size 50

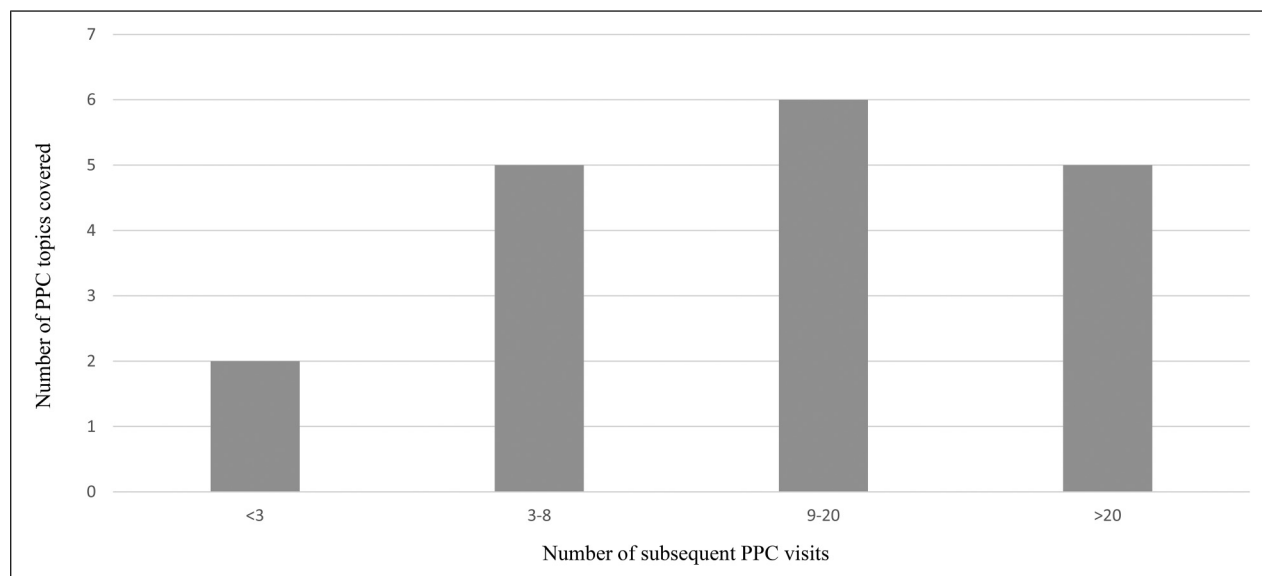
^cSample size 54

Table 2. Characteristics of Pediatric Palliative Care (PPC) Consults (N = 56)

Characteristic	n	%	Mdn	IQR		
Age at time of PPC consult, years			13	7, 19		
Time from diagnosis to PPC consult, days			532	242, 988		
Children who had subsequent PPC visits after the initial consult	49	88				
Number of subsequent PPC follow up visits			9	2, 20		
Time from initial PPC consult to death, days			68	23, 154		
PPC topics ^a	Primary team reason for consult		Discussed at initial consult		Discussed at a follow-up visit	
	n	%	n	%	n	%
Pain management	31	55	48	86	44	79
Non-pain symptom management	18	32	28	50	42	75
Goals of care/decision-making	9	16	16	29	26	46
Coordination of care/home care/hospice	6	11	9	16	26	46
Psychosocial support	5	9	22	39	26	46
Withdrawal or withholding of interventions/end-of-life care	3	5	1	2	4	7
Advance care planning	2	4	4	7	24	43
Child life/ancillary services	1	2	2	4	13	23
Child/family quality of life	0	0	5	9	20	36
Spiritual support	0	0	1	2	12	21
Prognosis	0	0	0	0	14	25

Note. IQR = interquartile range.

^aMore than one topic could be discussed at any visit.

**Figure 1.** Number of subsequent PPC visits with range of palliative care topics covered.

the primary reasons for consult were pain and non-pain symptom management. The PPC team predominantly limited the topics covered in their initial consultation to pain and non-pain symptom management and then subsequently expanded to a variety of palliative care topics with patients and families over the course of their subsequent visits.

Findings from this study suggest that despite common misconceptions (Bogetz et al., 2019; Davies et al., 2008, Szymczak et al., 2018), PPC teams rarely venture into discussing prognosis, EOL care, or advance care planning in their initial visits with children and families. This study complements existing literature on the reasons for consultation and range of needs addressed by the PPC team

(Feudtner et al., 2011; Vern-Gross et al., 2015) and highlights how the relationship between patients/families and PPC team unfolds over time.

Among consults for withdrawal of interventions/EOL care, coordination of care/homecare/hospice, and advance care planning, the child/family typically received ≤ 3 total visits from the PPC team prior to their child's death. This suggests that in these instances PPC consultation occurred late in the child's illness. When PPC is consulted for support at EOL in an imminently dying patient, it is reasonable that topics of discussion include goals of care and advance care planning. However, patterns of delayed PPC consultation such as those seen in this study may perpetuate oncology clinician concerns that the PPC team's primary role is in EOL care and that the team will immediately discuss EOL care when meeting the family. Other studies have shown that PPC teams often support children and families with complex medical conditions over years, yet among the oncology population consultation practices remain delayed until later in the illness trajectory (Feudtner et al., 2011). Late PPC consultation may mean that patients and families miss out on the psychosocial support and additional supportive services that PPC offers longitudinally.

For patients alive long enough for more than three total visits, the initial PPC visit most commonly included a discussion of pain management, non-pain symptom management, and psychosocial support. Rather than immediately jumping into difficult topics, our data suggests that PPC teams may be measured in their process of establishing a foundation of trust before broaching conversations regarding advance care planning, goals of care/decision-making, and coordination of care/home care/hospice. This highlights the importance of early consultation as PPC teams need time to develop relationships that allow for broader provision of palliative care for children and their families. These relationships are important for not only establishing rapport but also for PPC teams to better understand child and family's values and priorities. Pediatric oncology nurses can facilitate early PPC consultation through advocacy and providing education to the family and other clinicians on the services provided by PPC teams. Early consultation may also allow greater collaboration, information sharing, and mutual support between the PPC team and oncology clinicians as well as with psychosocial clinicians who may not be a part of the PPC team including social work and/or spiritual care providers.

These findings also suggest that when the PPC team has subsequent visits with children and families, they are able to extend their services to include discussions about quality-of-life issues and to facilitate connections with other supportive services in the hospital including child life and spiritual care. The PPC team can contribute to the multidisciplinary assessment of psychosocial, existential, and spiritual needs and collaborate with pediatric oncology

clinicians to promote quality of life for the child and family. Ensuring that children and families are provided with these supports is essential to comprehensive care of children with cancer (Robert et al., 2019) and can have an impact on bereavement (Lichtenthal et al., 2015). PPC collaboration may also help alleviate pediatric oncology team member distress and burnout (Granek & Buchman, 2019).

There are several important limitations to this single-site study. While this study demonstrates the context and content of PPC consultation at a tertiary academic children's hospital with a medium-sized pediatric oncology program and robust stem cell transplant service, these findings may not reflect the consult patterns of PPC teams across the United States, which are heterogeneous (Feudtner et al., 2013). While typical of PPC services nationally at the time, the model of PPC service delivery at the study site evolved over the study period (Friedrichsdorf & Bruera, 2018). PPC team staffing, training, and certification may have influenced the acceptability of PPC consultation and the interventions provided by the PPC team. Furthermore, while many children with cancer receive outpatient treatment, during the study period PPC services were predominantly inpatient, thus late consultation patterns may reflect challenges in accessing PPC. Furthermore, only children who died from relapsed/refractory cancer were included and may not have represented consult patterns for children with cancer who did not die from their disease. We suspect that the children included in this study may have had higher symptom burden due to their disease status, and as such the consult reasons and interventions may have been skewed toward symptom management. Additionally, patients were identified through a manually maintained database of deaths that may not have captured all deaths over the study period. Data was collected from documentation in the electronic medical record, which may have misrepresented what was discussed in actual PPC visits and does not capture whether the PPC team or the family-initiated discussions on each topic. We also did not assess whether the child's primary oncology team had discussed prognostic information with the child/family, which may have impacted the PPC team's decision to not bring this topic up during their first visit with families. Future studies should evaluate consult characteristics in real-time to help identify opportunities for additional targeted education and collaboration between pediatric oncology clinicians and PPC teams.

Conclusions

This study highlights how PPC consultation with children and their families facing relapsed/refractory cancer may unfold between initial and subsequent visits. Despite misconceptions about palliative care consultation, the PPC team in this study primarily discussed pain and non-pain symptom management and did not discuss

prognosis at any initial visit. Rather, this study suggests that PPC teams cover sensitive topics at the initial visit only when PPC consultation occurs very late in the disease trajectory and when explicitly requested by the oncology team. When PPC was consulted earlier to enable subsequent follow-up visits, the PPC team was able to support families by covering a wide range of important topics and ensuring that they received the comprehensive multidisciplinary services essential to support for children and families through EOL and bereavement.

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Declaration of Conflicting Interests

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