



HHS Public Access

Author manuscript

J Pain Symptom Manage. Author manuscript; available in PMC 2022 April 04.

Published in final edited form as:

J Pain Symptom Manage. 2020 May ; 59(5): 1033–1042.e1. doi:10.1016/j.jpainsymman.2019.11.022.

Defining the Boundaries of Palliative Care in Pediatric Oncology

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Abstract

Context.—Although palliative care (PC) continues to be integrated into pediatric oncological care, only a minority of patients with cancer receive a formal PC consult.

Objectives.—We sought to describe oncologists' current understanding of PC and how primary PC is provided for children with cancer.

Methods.—This mixed-methods study explored pediatric oncology providers' definitions of PC and self-reported PC practices through semistructured audiotaped interviews. Conventional content analysis was applied to interview transcripts.

Results.—Seventy-seven participants with diverse training backgrounds (30 attending physicians, 21 nurses, 18 fellows, five nurse practitioners, and two child life specialists) completed an interview. Approximately 75% provided a modern definition of PC (e.g., not limited to end-of-life care); all participants acknowledged primary PC skills as part of their daily clinical activities. However, participants expressed wide variation in the comfort and time spent performing primary PC tasks (i.e., symptom management, addressing mental health and psychosocial needs) and over half reported that patients' PC needs are not adequately met. In addition, some reported confusion about the benefits of PC consultation, despite acknowledging that PC needs to be better integrated into the care of pediatric oncology patients.

Conclusion.—Our findings demonstrate that although most pediatric oncologists accept a modern definition of PC in theory, how to integrate PC into pediatric oncology practice is less understood. Formalized training and standardization of practice surrounding identification of PC

needs in patients who may require secondary or tertiary PC services may help to overcome current barriers for PC integration in pediatric oncology.

Keywords

Palliative care; pediatric oncology; quality of life; symptom management

Introduction

With the rising incidence of cancer in children, more patients are undergoing cancer treatments and experiencing their negative side-effect profiles.¹ This is particularly evident with evolving therapies like chimeric antigen receptor T cell (CAR T) agents, which also amplify prognostic uncertainty.² Despite pediatric oncology advances, one in five children with pediatric cancer in the U.S. will die each year from their disease- or therapy-related complications.³

In 2008, Wolfe et al.⁴ reported that children with cancer who received optimal palliative care (PC) at the end of life experienced less suffering. Several additional studies have demonstrated the benefit of integrating PC into the care of pediatric oncology patients,^{5,6} including improvement in quality of life, symptom distress, illness understanding, satisfaction with care, and overall survival.⁷ This evidence supports the integration of PC as a component of routine care for pediatric patients with life-threatening illness as a professional standard.⁸ In addition, to reduce suffering and augment quality of life regardless of lifespan, the American Society of Clinical Oncology (ASCO) and the American Academy of Pediatrics (AAP) advocate for PC involvement for these children and their families.^{9,10}

Over the past decade, access to PC has become more uniform across the U.S., yet data suggest that only a minority of children with cancer receive PC services.¹¹⁻¹³ A systematic review conducted by Cheng et al.¹⁴ reported that only an estimated 55% of children who died from cancer received any form of PC at the end of life. The number is likely even lower for patients who survive their illness. A qualitative study of pediatric oncologists suggests that differing philosophies between oncology and PC and emotional hesitancy or reluctance by both the patient/caregiver and the oncologist are barriers to early integration of PC.¹⁵ The degree to which pediatric oncologists incorporate elements of primary PC (i.e., basic symptom management, goals of care discussions, hospice referral) into their practice is unknown.

We designed this multicenter study to 1) assess pediatric oncology practitioners' understanding of PC (i.e., how they define PC), 2) describe the extent to which PC is integrated into current care via primary PC delivered by the oncologist (i.e., amount of time spent on PC needs, extent to which patient PC needs are met, elements of primary PC provided such as basic symptom management, routine discussions on goals of care, code status, and transition to hospice), and 3) describe reported barriers to PC provision to pediatric oncology patients (i.e., provider discomfort providing primary PC and tensions between oncology and subspecialist PC teams). These results identify potential gaps in PC integration in pediatric oncologic care and may be used to develop targeted PC interventions.

Methods

To answer the current research questions, we recruited pediatric oncology providers (attending physicians, fellows, nurse practitioners [NPs], child life specialists, and inpatient and outpatient nurses) from two academic medical institutions to participate in a semistructured interview (Tables 1 and 2). Study approval was obtained from both the NIH Office of Human Subjects Research Protection and the Johns Hopkins Institutional Review Board (IRB); the study was deemed IRB exempt as per federal guidelines on human subject research.

All pediatric oncology providers were eligible for participation in this study. A total of 66 recruitment e-mails were delivered to 33 attending physicians, 18 fellows, 10 outpatient nurses, and five nurse practitioners. Three attending physicians did not respond to initial or follow-up e-mails and thus did not participate in this study. Inpatient nurses were recruited by one e-mail sent to the inpatient nurse coordinator who distributed to all inpatient nurse employees. Participants were chosen on a first-come basis. The oncology groups' child life specialists who participated in this study requested inclusion. In total, 77 interviews were conducted to allow for a robust representation of key provider level perspectives—attending, trainee, nursing (both inpatient and outpatient), and nurse practitioner. This number also allowed for thematic saturation.

In-person semistructured interview prompts were developed through a literature search and expert review (Appendix). One study team member, a pediatric oncology trainee, who received training in semistructured interviewing methodology from senior study members and online educational resources, conducted all interviews. Interviews were audio-recorded and transcribed. Transcripts were analyzed using Dedoose qualitative analysis software and a mix of conventional and summative content analysis.¹⁶

Pediatric Oncology Practitioners' Understanding of PC

Participants were first asked to provide their own definition of PC. Responses were analyzed for recurrent themes by the frequency in which they emerged from the individual interviews by using methods of grounded theory.¹⁷ Subthemes were grouped under larger themes based on contextual meaning. For example, comprehensive care was used in the context of describing treating the whole patient and improving their quality of life and thus judgment was made to include these codes under a broader quality of life theme. The same theory was applied to include the subtheme of goals of care under a broader psychosocial umbrella. This method was applied to all qualitative interview questions. Discrepancies among reviewers were resolved through repeated discussion.

PC Integration in Pediatric Oncologic Care

After providing their individual definition for PC, participants were read aloud the World Health Organization (WHO) definition for PC, "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems—physical, psychosocial,

and spiritual.¹⁸ To assess primary PC provision, participants were subsequently asked to describe how much of their day-to-day clinical work reflects the WHO definition of PC (i.e., skills used to deliver primary PC and time spent performing PC services). Participants were then asked to describe how well they believed that the PC needs of their pediatric oncologic patients are met in general.

Barriers to PC Provision to Pediatric Oncology Patients

Participants also described elements of primary PC that they are less comfortable with providing. Finally, tensions between pediatric oncology and PC were explored as potential barriers to subspecialist PC consultation.

Results

Seventy-seven participants were interviewed between June and August of 2018. Participants included 30 attending physicians, 21 inpatient and outpatient nurses, 18 fellows, five NPs, and two child life specialists. Participants had varying levels of experience (from six months to over 25 years) practicing in pediatric oncology (Table 1). Table 2 describes the two academic institutions from which participants were recruited.

Pediatric Oncology Practitioners' Understanding of PC

When prompted to define PC, participants' responses aligned with four main themes: 1) end-of-life care (mentioned by 50% of attending physicians, 55% of fellows, 80% of NPs, 76% of nurses, and 50% of child life specialists), 2) focus on quality of life (e.g., symptom management and comprehensive care or treating the whole patient to improve their quality of life; mentioned by 83% of attending physicians, 100% of fellows, 80% of NPs, 100% of nurses, and 100% of child life specialists), 3) psychosocial care (including interdisciplinary team discussions around goals of care to ameliorate or ease psychosocial stressors; mentioned by 57% of attending physicians, 78% of fellows, 60% of NPs, 46% of nurses and 50% of child life specialists), and 4) spiritual care (mentioned by 7% of attending physicians, and 5% of nurses) (Table 3). There was frequent mention of how PC historically meant solely end-of-life care but that this definition has evolved within the field of pediatric oncology.

When I was a fellow a long time ago, palliative care meant end-of-life care, and for some, it might still mean that. I actually believe that it no longer means that.

(Attending)

I think a lot of people initially think it's the same as hospice care, but it's not.

(Nurse Practitioner)

Participants suggested that trainees might demonstrate a greater comfort and familiarity with PC and willingness to consult this subspecialty than more senior providers.

I think, and this may be more the older faculty that have issues with this, I feel like there're faculty members who have a hard time saying, 'We've done enough. It's time to transition toward focusing on quality of life rather than cure at this point.

(Attending)

PC Integration in Pediatric Oncologic Care

Participants were asked to describe what PC skills they use in their daily practice, and a gap between knowledge and practice emerged. Several pediatric oncology providers stated that they find it hard to straddle the definition of both oncology and PC in practice due to competing philosophies.

[In] some cases, certain conversations may be better handled without necessarily the oncologist having to straddle the fence to some extent.

(Attending)

One of the things that came up right away is that [PC] is not [just] end-of-life care. Most of us know to say that. In our practice, we don't always view it that way.

(Fellow)

Every participant, regardless of provider role, reported that some portion of their day-to-day care for pediatric cancer patients included tasks that meet the definition of PC. Fig. 1a illustrates the breakdown of time spent on PC tasks by provider role. Approximately half (53%) felt that the majority of their time with patients was spent addressing PC needs. The remaining 47% felt that less than half of their time was spent on PC issues, with 14% reporting very little time (<25%) focused on these issues (Fig. 1a). The examples of PC-related tasks that pediatric oncologists perform regularly included end-of-life care (mentioned by 30% of attending physicians, 30% of fellows, 20% of NPs, and 20% of nurses), psychosocial care (mentioned by 36% of attending physicians, 21% of fellows, 14% of NPs, and 25% of nurses), and symptom management (mentioned by 78% of attending physicians, 41% of fellows, 20% of NPs, and 57% of nurses) (Table 4). In addition, many oncologists feel that they are meeting their patient's PC needs (Fig. 1b), although approximately half of the respondents (54%) suggested that providers could do a better job at this (Fig. 1b).

Barriers to PC Provision to Pediatric Oncology Patients

Discomfort Providing Primary PC.—Participants were asked which PC needs they feel least comfortable addressing. End-of-life care, especially difficult discussions around conflicting goals of care, was a common theme (mentioned by 68% of attending physicians, 43% of fellows, 14% of NPs, and 60% of nurses), as was quality of life, specifically management of uncontrolled symptoms (i.e., with complimentary medicine (mentioned by 64% of attending physicians, 84% of fellows, and 20% of nurses), mental health needs (mentioned by 45% of attending physicians, 23% of fellows, and 23% of nurses), and spiritual needs (mentioned by 57% of attending physicians, 18% of fellows, and 18% of nurses) (Table 5). One-third of respondents reported complete comfort providing PC (mentioned by 44% of attending physicians, 25% of fellows, 6% of NPs, and 25% of nurses).

I don't think that there's a lot of times where you have to call somebody else. I've just had a lot of experience.

(Nurse Practitioner)

Others felt that, regardless of skill level, having someone outside of the oncology team assist patients and families with difficult situations is extremely valuable.

I think there is a benefit to having an external person, outside of your oncologist, be the person who you think about and talk about these types of things with.

(Fellow)

Tensions Between Subspecialty Palliative Care and Oncology.—Although nearly every participant (98%) described the need for increased and earlier use of subspecialty PC services, some participants also reported ongoing discordance between PC and oncology (Table 6). Reports of language surrounding cancer treatment that is cure driven (e.g. “trying for a cure,” “going for the touchdown”) were described by some participants as inconsistent with providing primary PC and consulting a PC service.

I don’t want to bring in the concept of conflict too much, but sometimes there is a conflict between palliative care specialists and physicians. I think they’re trained differently and their philosophies are different We [oncologists] are trained to fight disease. We are trained not to accept defeat.

(Attending)

In addition, some participants reported that oncologists may be less likely to get PC teams involved because they say that they can provide these types of services themselves and do not understand the added value of PC consultation or are reluctant to delegate aspects of their patients’ care to others (Table 6). Finally, participants reported that many parents do not want their oncology providers to stop looking for a cure and families may be reluctant to utilize or are even offended by the suggestion to involve PC because of its association with giving up hope or end-of-life care.

Discussion

This multicenter study of a diverse group of pediatric oncology providers allows for a unique perspective on the current opinion of PC and its role within pediatric oncology. Importantly, the participants reveal an evolving understanding of PC among pediatric oncologists that extends beyond end-of-life care and highlight ongoing opportunities to close gaps between PC knowledge and practice. Participants had differing levels of comfort with primary PC skills, varying levels of awareness of PC benefits, and persistent concerns about integrating PC for some pediatric oncology patients.

Historically PC, especially in oncology, quickly became associated with the terms “end of life” and “hospice.”¹⁹⁻²¹ Our findings suggest that the working definition of PC by pediatric oncology clinicians and researchers is expanding and is no longer limited to hospice-related services. Although there were still some oncology providers who believe PC to be EOL care, the majority understand PC more holistically and reflective of the current WHO definition, “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention

and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.¹⁸” Specifically, we found that nurses and advanced level providers were more likely to include EOL in their definition of PC and that fellows were the largest reporter of psychosocial aspects of care in their definition of PC. Interestingly, almost all participants cited improving quality of life through either symptom management or comprehensive care as part of their PC definition and very few commented on spiritual concerns as a part of PC. We hypothesize that this may be reflective of differences in education both through theoretical (medical school, nursing school, etc.) and practical training (residency, fellowship, etc.); however, further investigation would be needed to better understand this. In addition, with increasing PC training courses like Education of Palliative and End of Life Care for Pediatrics (EPEC-peds), these interprofessional discrepancies may be improving.²²

Regardless of the definition for PC provided, we found that many oncology providers feel that PC should be integrated much earlier in the care of children with cancer. This likely reflects the growth and availability of PC services in hospitals across the U.S., as well as increasing pediatric oncology exposure and experience with subspecialized PC services.¹¹ Yet, a minority of children with cancer are receiving PC consultation,²³⁻²⁵ which begs the question “Is the pediatric oncologist providing PC services?” and if so, “Are we meeting our patients’ PC needs?”²⁶.

Across the U.S., efforts are increasing to improve team-based, interdisciplinary oncology care, to include PC.^{27,28} In our study, pediatric oncology providers, regardless of role, subspecialty, or years of experience, feel that PC is a part of their daily clinical practice. This reinforces that primary PC is a part of the primary oncologist’s role; however, the wide variation of time spent performing PC tasks, and the fact that 79% of participants reported only “fair” or worse success in meeting their patients’ PC needs, all suggest there is a room for improvement. In addition, although many participants defined PC in holistic terms, many of their primary PC practices are still limited to EOL care and hospice referral. Our data addresses the aspects of primary PC with which pediatric oncology providers are uncomfortable.

Approximately two-thirds of attending physicians and nurses reported discomfort with end-of-life or “difficult” conversations. We hypothesize discomfort to be highest in these groups as attending physicians are generally leading EOL discussions and nurses tend to spend a greater amount of one-on-one time with the patients and their families. Other areas of discomfort in PC management included psychosocial matters, addressing mental health needs and managing difficult symptomatology. Once again, spiritual needs were infrequently mentioned. These results highlight potential education targets in pediatric oncology so that clinical practice can reflect the growing PC knowledge and understanding as demonstrated through an evolved PC definition.

The American Academy of Pediatrics describes health care communication as a “critical, but generally neglected, component of pediatric and pediatric subspecialty practice and training.²⁹” This is particularly problematic in pediatric oncology, where so much of patient care revolves around difficult conversations and sometimes EOL care and was highlighted as

an area of discomfort among participants in this study. In 2007, Baker et al.³⁰ performed a national survey of pediatric residency directors and trainees regarding educational exposure to PC concepts. Only 38% of residency directors felt that their trainees were receiving adequate training in PC core competencies, and many residents felt unprepared to practice PC skills after completion of residency. A follow-up study by Michelson et al.³¹ in 2009, which included pediatric residents and fellows, also supported this finding that trainees were receiving little to no formalized training in PC skills, and desired a formalized curriculum. A decade later, our study suggests that trainees continue to feel uncomfortable in practicing primary PC skills and perhaps incorporating PC into training programs, especially subspecialties like pediatric oncology where patients are facing life-threatening diseases and toxic therapies, is a way to improve the overall integration of PC into the care of children with cancer.

Aside from lack of education, several additional barriers to PC integration, specifically in pediatric oncology, are reported in the literature.^{15,20,21,32-35} Most commonly, uncertain prognosis and family readiness to involve PC are cited, although other studies have shown that these concerns may be unfounded.^{32,36,37} In a recent study by Dalberg et al.¹⁹ in 2018, barriers to PC integration were categorized into four main groups: provider role (concern for overlap between PC and oncology provider, need for the oncologist to control all aspects of care), conflicting philosophies (oncology means fight and PC means giving up), family readiness, and emotional influence. These theories may explain the reluctance of pediatric oncology providers to consult PC and our study confirmed these barriers specifically in regard to provider role and conflicting philosophies. Some participants shared comments on how they continue to find it difficult to straddle both realms of oncology and PC, as if they were separate entities and not concurrent care with similar goals. Others also noted a generational or training divide between providers and their understanding of PC. As illustrated from our qualitative data, some participants felt that “everything we do is PC,” and as a result, they were unclear of the added benefit for subspecialty PC services. In addition, the cure-based culture of pediatric oncology likely prevents integration of PC into the care for children with cancer.¹² Language such as “fight” or “win” often used by participants in this study when referring to cancer care may contribute to these tensions, thus hindering PC integration. Despite these feelings, 98% of participants felt that we could improve the integration of PC into our care of pediatric oncology patients.

Although studies reporting on perspectives of palliative care by pediatric oncologists are plentiful in the literature, our study is unique in that it is the first to demonstrate that culture change is indeed occurring. Our findings suggest that the goal of increasing PC awareness is largely being achieved through increased provider knowledge and understanding of PC and as noted earlier, increasing data supporting positive effects. These definitions are being cited by oncology providers regardless of their professional role and years of experience, which is to say that even those who received oncology training before the days of a formalized PC subspecialty are recognizing the importance of this field. The challenge that remains is how to fully integrate PC within the practice of pediatric oncology. Our study shows that this is still a work in progress (i.e., discomforts with primary PC skills and reports of not adequately meeting patients’ PC needs). In addition, oncology and PC teams should be working toward a common goal for the patient and not in contrast as alluded to by some

participants. New goals to help improve the primary PC skill set of the oncology team and to increase subspecialty PC integration should become the focus. Specifically, recognizing PC needs and those patients who may require secondary or tertiary PC services, improving communication, and reevaluating goals of care regularly are skills that oncology training programs can emphasize to help bridge the gap between knowledge and practice. Further work to destigmatize PC and develop standardized tools for consultation may be helpful to facilitate early and regular integration of PC services for pediatric oncology patients.

In contrast to the recently reported study by Dalberg et al.¹⁹ on perceptions of PC and barriers to integrating PC in pediatric oncology, our study design focused primarily on defining PC in theory (definition of PC) and in practice (daily skills used to deliver primary PC). Our study population was robust and well represented by several members of an interdisciplinary care team. It also allowed pediatric oncologists the opportunity to describe when and how they decide to use PC services, something that quantitative data cannot fully capture. Yet, several study limitations exist. Participants were drawn from two large academic institutions, and results may not translate to other pediatric oncology practice settings. Oncologists' daily practices were assessed via self-report and are subject to recall bias. Interviews were conducted by one study member who is a pediatric oncology trainee; social desirability could have inflated reports of PC practices and impeded reports of PC barriers. Finally, although a sample size of 77 is respectable for a mixed-methods study, future quantitative research with a larger, nationally representative sample may expand on these findings to describe PC provision to pediatric oncology patients more broadly.

Conclusion

Despite better understanding of what PC can offer to patients and their family members, our data suggest that additional work is needed to consistently integrate PC into the everyday practice of pediatric oncology. Creative interventions to support the shared goal of improving care for pediatric oncology patients throughout their illness, not just at the EOL can be achieved in part by improving the primary PC skills of the oncology team.

Disclosures and Acknowledgments

The authors acknowledge the support of the pediatric oncology providers who participated in their study.

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. This study was supported, in part, by the Intramural Program of the National Cancer Institute, Center for Cancer Research.

Appendix: Interview Questions

1. First, can you describe what palliative care means to you?
2. What palliative care training have you had in the past, if any?

Ensure to include:

- a. Any formalized training

A common definition used to describe palliative medicine is an “approach that improves the quality of life of patients and their families facing the physical, psychosocial, and spiritual problems associated with life-threatening illness through prevention and early identification.”

1. On a day-to-day basis, what aspects of the care that you provide to your pediatric oncology patients do feel are similar to what we just described as palliative medicine?
2. Is there anything in particular that falls under this definition for palliative medicine that you feel less comfortable in managing?
3. How well do you think that pediatric oncology providers are able to meet the palliative needs of their patients?
4. What do you think that pediatric oncology providers currently do well related to palliative needs of their patients?
5. Are there ways we can improve?
6. Is there anything that you can think of that would trigger you to consult palliative medicine?

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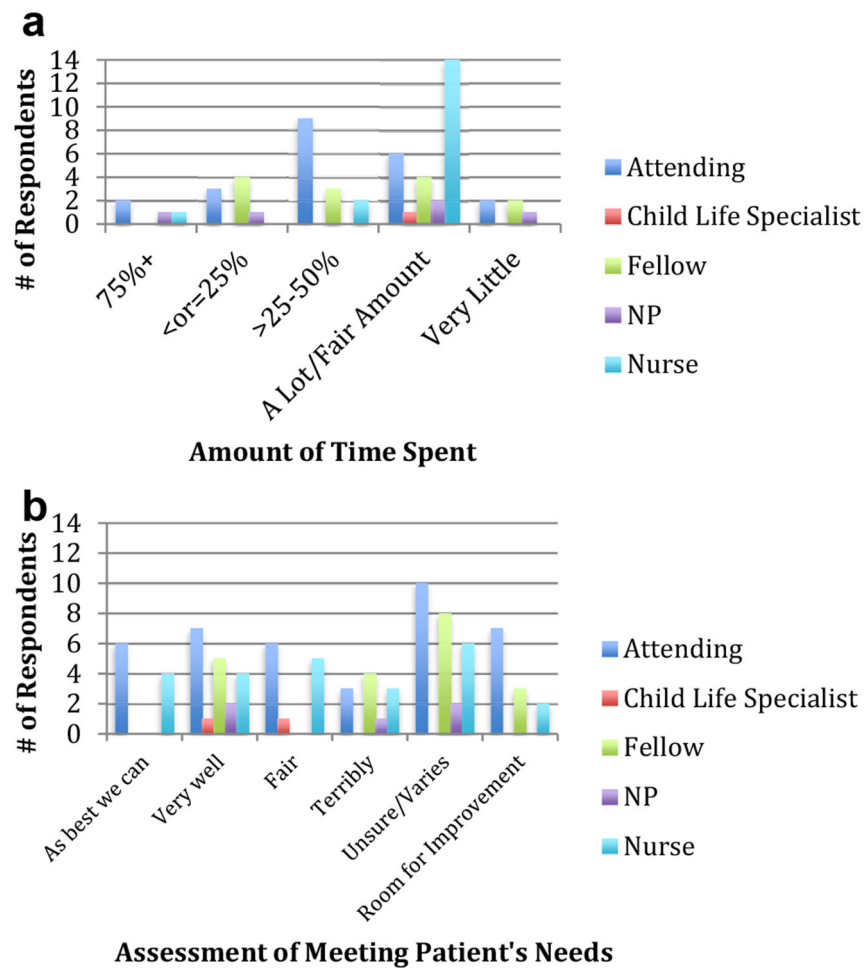


Fig. 1. Perceived palliative care needs and time spent meeting those needs of pediatric oncology patients. a) Demonstrates the amount of time felt to be spent addressing palliative care needs by pediatric oncology providers and b) describes the perception of how well pediatric oncology providers feel that they are meeting their patients' palliative care needs.

Table 1

Participants Demographics

	No. of participants
Role	
Attending physician	30
Fellow	18
Inpatient nurse	11
Outpatient nurse	10
Nurse practitioner	5
Child life specialist	2
Years practicing	
0.5–2 yrs	16
>2–5 yrs	19
>5–10 yrs	17
>10–25 yrs	12
>25 yrs	8
Subspecialty	
General oncology	44
Leukemia & lymphoma	11
BMT	7
Neuro-oncology	6
Sarcoma/solid tumor	6
Bone marrow failure	1
Child life	2
Survivorship	1

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Table 2

Institution Characteristics

Institution Characteristics	Institution A	Institution B
Annual pediatric oncology patients treated	>300	120
ICU acuity	Y	Y
Palliative care (PC) team	Y	Y
Pediatric-specific PC team	Y	N
Members	One attending physician, two fellow physicians, one child life specialist, one chaplain, two nurses	N/A
Pain team	Y	N

“What Does Palliative Care Mean to You?”—Definitions of Palliative Care by Pediatric Oncology Providers

Theme	Examples
End of life/hospice	<ul style="list-style-type: none"> • “To me, palliative medicine is the care of patients who you assume end of life is coming.”—Fellow • “I think of palliative medicine as a subspecialty that helps patients and families with the challenges of end of life.”—Attending • “We think of it more toward the end of life, but it should be thought of more throughout the whole entire treatment process.”—Nurse Practitioner • “Giving patients the best care in all aspects, especially when end of life is in mind.”—Inpatient Nurse
Psychosocial care	<ul style="list-style-type: none"> • “It takes in their psychosocial, who they are as an actual person and their family.”—Inpatient Nurse • “There’s a lot of focus on the patient and the family, the caregivers rather, not necessarily just family the spiritual, psychosocial, and physical well-being of the patient and their family.”—Outpatient Nurse • “The way I understand it is it’s an encompassing way of managing the psychosocial stressors associated with life-threatening diagnoses.”—Attending
Quality of life	<ul style="list-style-type: none"> a. Goals of care <ul style="list-style-type: none"> – “It’s a restructuring of goals of care to some degree.”—Attending – “[It’s] honoring what those goals of care are.”—Fellow • “I think it tends to be the big umbrella for quality of life.”—Attending • “I feel like palliative care, I feel like they’re experts in quality of life, balancing the medical with, again, the social and the psychosocial, and just humanizing the treatment.”—Child Life
Spiritual	<ul style="list-style-type: none"> a. Symptom management <ul style="list-style-type: none"> – The general concept is that it’s not just symptom management for end-of-life care but, in general, throughout the course of a patient’s treatment. Managing their symptoms and give them the best quality of life within the goals of the treatment and their goals for their care.”—Fellow – “I think it’s about supporting symptom management, reducing suffering in any way that we can.”—Attending b. Comprehensive care <ul style="list-style-type: none"> – “Palliative medicine means the aspect of medicine that takes into account the whole patient, and what it means for that patient to have as good of a quality of life at that time given all comorbidities, psychosocial issues, and various multidisciplinary needs.”—Fellow – “Palliative medicine is like holistic care for patients regardless if they’re at end of life or not.”—Inpatient Nurse • “When you know of a person’s religion and you know that it’s essentially something important to them, there’s a lot of things we’ll do . . . to maintain as much normalcy as possible for them and to keep true to their traditions.”—Inpatient Nurse

Table 4 “On a Day-to-Day Basis What Palliative Care Skills Do You Practice?”—Examples of Palliative Care in Daily Pediatric Oncology Practice

Theme	Examples
End-of-life care	<ul style="list-style-type: none"> • “Even though I know that palliative care [pause] it’s moving away from being associated with hospice and end of life care, the picture I’m painting in my mind with it and the experiences I’ve had with it are largely dealing with end of life patients.”—Outpatient Nurse • “Usually, we don’t call on the palliative care team until it’s a poor prognosis or a relapse. Essentially, somebody who we might still provide treatment for, but that we are pretty certain that it’s not going to be curative.”—Inpatient Nurse
Quality of life	<ul style="list-style-type: none"> • “I’m focused on quality of life. I’m focused on long-term development.”—Child Life • “When you think about it, a lot of it is trying to make their quality of life as best you can, whether it’s simple things with scheduling their appointments.”—Outpatient Nurse • “We spend a lot of time thinking about quality of care.”—Nurse Practitioner <p>a. Symptom management</p> <ul style="list-style-type: none"> – “It’s not actually the administration of chemotherapy, but focused on quality of life issues. Whether it’s improving nausea medicines, worrying about appetite and weight, making sure that patients spend as much time out of the hospital as possible.”—Attending – “Oh gosh, it’s so much of what we do. Oncology nursing is a funny thing in some ways because so much of what we do . . . it’s so painful and contrary to quality of life. Then we spend probably more energy trying to undo the side effects of what we’ve done.”—Inpatient Nurse – “A lot of our care is palliative care. When a patient comes to clinic . . . We’re talking about things like pain, and nausea, and mood. The vast majority the appointment is really that comfort, that quality of life.”—Attending
“All of our care”	<ul style="list-style-type: none"> • “Everything we do should be in line with palliative care. In terms of the overarching treatment plan.”—Fellow • “My approach to nursing is founded in the idea that nurses are there to treat the whole person.”—Inpatient Nurse
Psychosocial care	<ul style="list-style-type: none"> • “I often say that the most important part of my job is in helping patients and families cope with what is going on with their disease and with its treatment.”—Attending • “In the context of patient family-centered care, to care for the entire family . . .”—Inpatient Nurse • “We’re quick to refer our patients for behavior guidance, depression, or psychiatric symptoms.”—Attending • “There are maybe one or two patients where they have difficult social situations in terms of financial means and trying to check up and make sure that they’re doing OK from a social standpoint.”—Fellow

Table 5
Areas of Palliative Care That Pediatric Oncologists Are Less Comfortable Providing

Theme	Examples
End of life	<ul style="list-style-type: none"> • “Whenever I have had a patient being referred to hospice or terminal care, I have definitely fallen back on the palliative care team. I don’t know, I don’t think I would feel uncomfortable having those discussions.”—Fellow • “I would say truly end-of-life care, and honestly having some of those end of life and goals of care discussions.”—Attending • “If they ask, “When am I going to die?” Actually tackling that whole thing.”—Inpatient Nurse
	<p>a. Home care needs</p> <ul style="list-style-type: none"> – “I don’t know the details of what they can and can’t do at home.”—Attending
	<p>b. Discordance</p> <ul style="list-style-type: none"> – “When there is differences across the provider team and the family about goals of care” —Attending – “I think we torture children sometimes. I just have to remember that it’s not my decision. That if a family thinks they’re doing the right thing and I think they should stop, it’s hard sometimes to deal with that.”—Outpatient Nurse
Quality of life	<ul style="list-style-type: none"> • “We normally will involve them when it feels like it’s beyond our control, our routine pain or nausea meds are just not cutting it, or they’re just having a particularly difficult course in general.”—Attending • “For me, it’s more getting more qualified people on board to provide the family the greatest extent of support that we can.”—Fellow
	<p>a. Symptom management</p> <ul style="list-style-type: none"> – “Very practical things such as pain control, optimal techniques, and methods of pain control and whether it’s balancing out issues between effect of narcotic doses as well as narcotic side effects” —Attending – “Where I have used them is a little bit more when I need help with complimentary alternative medicine approaches.”—Attending – “They seem to have a lot of resources that I don’t have, especially when it comes to approaches that are not traditional Western medicine.”—Fellow
	<p>b. Mental health</p> <ul style="list-style-type: none"> – “If there’s a lot of anxiety, depression, I would think to get them involved” —Fellow – “Things I don’t feel as comfortable doing or choose to have someone else help like psychological, mood disorders.”—Attending
	<p>c. Spiritual</p> <ul style="list-style-type: none"> – “I feel completely incapable of giving spiritual support.”—Attending – “I always call psychiatry ‘social work’ for its spiritual care needs because they’re not my forte.”—Attending

Table 6

Tensions Between Pediatric Oncology and Palliative Care

Theme	Examples
Already doing PC	<ul style="list-style-type: none"> • "It's actually a little source of contention. I don't know how to make it better but, here you are as an attending and/or a fellow, and you are trying to do your best, maybe you even think you are doing a good job. You are trying to address these things, and then there is the resident who's known the patient for two days, and is like, 'We should consult palliative medicine?' There's a part of me that wants to be like, 'What do you think I'm doing?'"—Attending • "I don't think you necessarily need another cook in the kitchen."—Attending
Unclear added value of PC	<ul style="list-style-type: none"> • "No, I'm not hesitant to get them involved but what are they going to do that I can't do?"—Fellow • "I don't know what I'm calling palliative medicine for. It's not that I haven't talked to the family about these issues. It's not that her current symptoms aren't being well managed. When do I need that consult?"—Attending
Conflicting philosophy	<ul style="list-style-type: none"> • "In oncology we play good cop, bad cop. We don't talk about that [PC]. They don't want to hear it from the same person that this might not work and you might die."—Attending <ul style="list-style-type: none"> a. "Giving Up" Message <ul style="list-style-type: none"> – "They think the team is giving up."—Outpatient Nurse – "There's the fear of introducing palliative care and hospice earlier because people are afraid that the message will be received and that it's as if we are losing hope."—Fellow – "It's a cultural thing and the families refuse palliative care because it really means they're giving up."—Fellow
Relinquish control	<ul style="list-style-type: none"> • "I think it's hard for us to relinquish that component of the patient's care to somebody else."—Fellow • "Sometimes I feel like you consult palliative care and it's like they're the primary team now. That, to me, has been very strange, that dynamic."—Attending