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Authors

LEVINE, ALYSSA

Winn, Phoebe

Fogel, Alexis

et al.

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Barriers to Pediatric Palliative Care: Trainee and Faculty Perspectives Across Two Academic Centers

Alyssa Levine, MD,¹ Phoebe A. Winn, MD,² Alexis H. Fogel, MD, MPH,² Efrat Lelkes, MD,³
Paula McPoland, MD,⁴ Anurag K. Agrawal, MD,⁵ and Jori F. Bogetz, MD⁶

Abstract

Objective: Barriers to palliative care for children with serious illness include system constraints and vastly different training and attitudes toward palliative care. This study aimed to explore trainee and faculty physician perceptions of barriers to palliative care across two pediatric centers to (1) examine differences between trainees and faculty and (2) compare these data with previous studies.

Methods: A mixed-methods study was conducted in fall 2021 among pediatric trainees and faculty physicians at three pediatric hospitals in two pediatric centers in the western United States. Surveys were distributed through hospital listservs and analyzed descriptively and through inductive thematic analysis.

Results: There were a total of 268 participants: 50 trainees and 218 faculty physicians. Of the trainees, 46% (23) were fellows and 54% (27) were pediatric residents. Trainees and faculty reported the same four most common barriers, which were consistent with previous studies: family not ready to acknowledge an incurable condition (64% trainees and 45% faculty); family preference for more life-sustaining therapies than staff (52% and 39%); uncertain prognosis (48% and 38%); and parent discomfort with possibility of hastening death (44% and 30%). Other barriers commonly reported included time constraints, staff shortages, and conflict among family about treatment goals. Language barriers and cultural differences were also cited.

Conclusions: This study examining palliative care across two pediatric centers suggests that providers' perceptions of family preferences and understanding of illness persist as barriers to the delivery of pediatric palliative care services. Future research should examine family-centered and culturally mindful interventions to better elucidate family perspectives on their child's illness to align care.

Keywords: communication; culture; education; palliative care

¹Department of Pediatrics, University of California, San Francisco, San Francisco, California, USA.
Divisions of ²Emergency Medicine and ⁵Oncology, Department of Pediatrics, UCSF Benioff Children's Hospital Oakland, Oakland, California, USA.

³Division of Pediatric Critical Care, Benioff Children's Hospital San Francisco, University of California, San Francisco, San Francisco, California, USA.

⁴Division of Pediatric Bioethics and Palliative Care, Department of Pediatrics, University of Washington School of Medicine, Seattle Children's Hospital, Seattle, Washington, USA.

⁶Division of Pediatric Bioethics and Palliative Care, Department of Pediatrics, Center for Clinical and Translational Research, Seattle Children's Research Institute, University of Washington School of Medicine, Seattle, Washington, USA.

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Introduction

CHILDREN WITH SERIOUS ILLNESS have diseases that are diagnosed as both acute and chronic.¹ Although the prognoses of these conditions are often uncertain, many are inherently life-threatening or life-limiting.^{2,3} Because of the variable and heterogeneous nature of conditions associated with serious pediatric illness, a wide variety of clinicians interact with this group of patients. This includes general pediatricians, pediatric subspecialty clinicians, and clinicians at all levels of training ranging from residents to fellows and faculty physicians.⁴

These clinicians are often expected to provide important counseling regarding goals of care, psychosocial support, and end-of-life (EOL) care to families of children with serious illness. However, these clinicians have a wide range of experiences and comfort providing this type of care.⁵⁻⁷

To address this variability in pediatric care, the American Academy of Pediatrics (AAP) recommends utilization of an integrated palliative care program at the time of diagnosis of a life-limiting disease.^{8,9} Over the course of the past two decades, pediatric palliative care (PPC) has expanded rapidly, with more than 60% of children's hospitals now having established programs.¹⁰ It is well accepted that PPC services lead to improved outcomes, including better overall family comfort in communication and decreased EOL symptom burden.

Despite this knowledge, existing literature suggests that a distinct lack of adequate resources remains and palliative care continues to be underutilized in pediatrics.¹¹⁻¹³ Barriers to delivery of PPC, which have been reported, include lack of adequate training among clinicians, language/cultural barriers, uncertain prognosis, and overall family/physician attitude toward involvement of palliative care.^{9,12,14-16} Reimbursement and outdated payment models have also been cited as significant obstacles.⁹

Identification of barriers to the delivery of palliative care by both primary and specialized palliative teams for children with serious illness and their families is an important step in moving toward developing systems with more robust and developed palliative care services for children and families.

This study aims to explore trainee and faculty physician perceptions of barriers to palliative care across two pediatric centers to (1) examine differences between trainees and faculty and (2) compare these data with previous studies.

Methods

This was a mixed-methods survey-based study conducted in the fall of 2021 at three pediatric hospitals in two pediatric centers in the western United States, each of which have their own unique PPC services and approach to trainee programs. Seattle Children's Hospital has a long-standing multidisciplinary PPC team that primarily focuses on inpatient consultation throughout the hospital and has a robust education program on communication and symptom management for residents and fellows.

University of California, San Francisco (UCSF), includes campuses in San Francisco and Oakland and is working to integrate services between the two campuses and trainee programs. Similar to Seattle Children's Hospital, each UCSF

campus focuses on inpatient consultation with a growing multidisciplinary team of palliative care and pain-focused providers, social workers, and child life specialists, all of whom actively participate in resident and fellow education on symptom management and bereavement.

The surveys were developed using surveys from existing similar studies to facilitate comparison over time.¹⁶⁻¹⁸ The survey had two components: the first component aimed to assess the frequency of current barriers to referrals and the second component aimed to assess the perceived degree of training and competence in areas related to palliative care. The survey was reviewed by a multidisciplinary cross-site research team that included pediatric residents, palliative care researchers and educators, subspecialty faculty physicians, and an ethicist before distribution.

The survey consisted of 40 discrete items with one open-ended response question inviting participants to provide free-form reflection on personal experiences with palliative care barriers. Demographic information collected included the clinical role, site/center, medical specialty, approximate number of deceased patients cared for in the previous 12 months, and approximate number of patients who were cared for and had received palliative care consultation in the previous 12 months.

The frequency of barriers encountered was assessed using a 5-point Likert scale, ranging from "always, frequently, sometimes, seldom, never" and "beginner, somewhat experienced, very experienced, expert." Perceived competency was assessed on a 4-point Likert scale, ranging from "beginner" to "expert." Four additional items assessed the personal needs for palliative care skill development and interest in educational opportunities. Surveys (Supplementary Data S1) were sent through Qualtrics (Qualtrics, Provo, UT) to listservs of residents, fellows, and faculty physicians at the participating centers, with two e-mail reminders sent by a member of the research team over the subsequent six weeks.

Data were analyzed using descriptive methods, with responses to barriers aggregated into two categories, including always/frequently and sometimes/seldom/never. Open-ended response items were explored through inductive thematic analysis for supplemental insight into factors contributing to barriers. The Institutional Review Board (IRB) at both sites approved this study.

Results

Demographics

There were a total of 268 participants: 50 trainees and 218 faculty physicians (Table 1). Of the trainees, 46% (23) were fellows and 54% (27) were pediatric residents. There were roughly an equal number of participants from the two pediatric centers. General pediatrics represented the largest group of respondents, with 50% (25) of trainees and 13% (28) of faculty physicians; the remainder largely self-identified as specialists in critical care, hematology/oncology, cardiology, and a range of other subspecialties.

Recent exposure to EOL experiences was common; 78% (39) of trainees and 78% (171) of faculty physicians reported caring for at least one child who died in the prior 12 months. Eighty-eight percent (44) of trainees and 81% (178) of faculty physicians reported having a child on their service, followed by palliative care, in the last 12 months.

TABLE 1. DEMOGRAPHICS

Characteristic	Trainees n = 50 (%)	Faculty physicians n = 218 (%)
Level of training		N/A
PGY 1	7 (14)	
PGY 2	13 (26)	
PGY 3	7 (14)	
Fellow	23 (46)	
Pediatric center		
Center 1—Site 1	12 (24)	53 (24)
Center 1—Site 2	14 (28)	62 (28)
Center 2	24 (48)	102 (47)
No response/unknown	0 (0)	1 (0)
Specialty		
General pediatrics	26 (52)	28 (13)
Hematology/oncology	4 (8)	20 (9)
Endocrinology	0 (0)	1 (0)
Gastroenterology	2 (4)	7 (3)
Cardiology	1 (2)	10 (5)
Nephrology	3 (6)	4 (2)
Infectious disease	0 (0)	12 (6)
Pulmonology	2 (4)	13 (6)
Neurology	2 (4)	7 (3)
Surgery	0 (0)	8 (4)
Emergency medicine	1 (2)	7 (3)
Anesthesiology	0 (0)	17 (8)
Critical care	5 (10)	35 (16)
Radiology	0 (0)	1 (0)
Allergy/immunology	0 (0)	3 (1)
Palliative care	0 (0)	3 (1)
Other	4 (8)	42 (19)
Approximate number of patients on your service who have died in the past 12 months		
None	10 (20)	37 (17)
1–5	25 (50)	100 (46)
6–10	6 (12)	38 (17)
>10	8 (16)	33 (15)
Other/unknown/no response	1 (2)	10 (5)
Approximate number of patients on your service who received palliative care services in the past 12 months		
None	2 (4)	25 (11)
1–5	16 (32)	75 (34)
6–10	9 (18)	37 (17)
>10	19 (38)	66 (30)
Other/unknown/no response	4 (8)	15 (7)

N/A, not applicable; PGY, postgraduate year.

Barriers

Responses to items about perceptions of barriers to PPC delivery are shown in Figure 1. Trainees reported more frequent barriers to PPC delivery than faculty, except for inadequate support services for families (24% trainees and 27% faculty); insufficient knowledge of EOL pain management (12% trainees and 14% faculty); lack of available palliative care consult services (12% trainees and 13% faculty); and physician fear of legal action (6% trainees and 8% faculty).

The four most frequently reported barriers for both trainees and faculty were the same: family not ready to acknowledge an incurable condition (64% trainees and 45% faculty); family preference for more life-sustaining therapies than staff (52% trainees and 39% faculty); uncertain prognosis (48%

trainees and 38% faculty); and parent discomfort with possibility of hastening death (44% trainees and 30% faculty).

Other barriers reported by approximately one-third of trainees and about one-fifth of faculty physicians included systemic factors, such as time constraints and staff shortages, as well as communication factors, such as conflict among family about treatment goals and conflict between family and staff.

Additionally, language barriers and cultural differences were also cited as common barriers by both groups of participants. Barriers such as fear of addiction and staff avoidance of dying patients were perceived as occurring less often.

Training needs

Trainees reported more training needs than faculty physicians (Fig. 2). Specifically, trainees reported feeling less confident in their ability to communicate with dying patients (48%, 24) and to be present with dying patients at the end of life (48%, 24). These skills were also the areas in which faculty most frequently identified their confidence level as “beginner” level (16%, 36, and 21%, 46, respectively). Less than 10% of trainees reported feeling like experts in each of the palliative care training areas assessed, although in general, they reported the most comfort in introducing the concept of palliative care (22%, 11).

In contrast, about 10%–15% of faculty physicians reported feeling like experts in all of the training areas assessed. Around two-thirds of all those self-reporting expert-level confidence in the areas assessed came from specialties that often care for patients at the end of life, including hematology/oncology, emergency medicine, anesthesia, critical care, and palliative care.

Opportunities for palliative care skill development and educational enrichment were important to trainees and faculty alike, with 76% (38) of trainees and 68% (148) of faculty endorsing that knowing how to care for dying children was one of the most important parts of their job. Over 90% of respondents endorsed the importance of palliative care education for clinical staff, and 70% (35) of trainees and 51% (112) of faculty physicians expressed interest in having a regular resource available to support them in caring for patients with palliative care needs.

Eighty percent (40) of trainees and 62% (136) of faculty physicians were interested in an annual course on pediatric palliative and EOL care for hospital staff (Fig. 3).

Themes related to barriers to palliative care

Open-ended responses revealed common themes shared by trainees and faculty physicians that were similar to survey responses (Table 2). Themes that facilitated palliative care provision and limited barriers included anticipating and clarifying EOL plans in an iterative manner to make advance care planning a longitudinal rather than acute process, fostering trust and connection with staff and families, and families being able to be with their child at the end of life.

Themes that diminished the efficacy of palliative care and acted as barriers included an uncertain prognosis and/or rapid decline in the child’s health; limited cultural diversity of clinicians; family and staff distress about conflicting treatment goals; inadequate resources, planning, and communication within teams to address EOL events; and inconsistent palliative care definition.

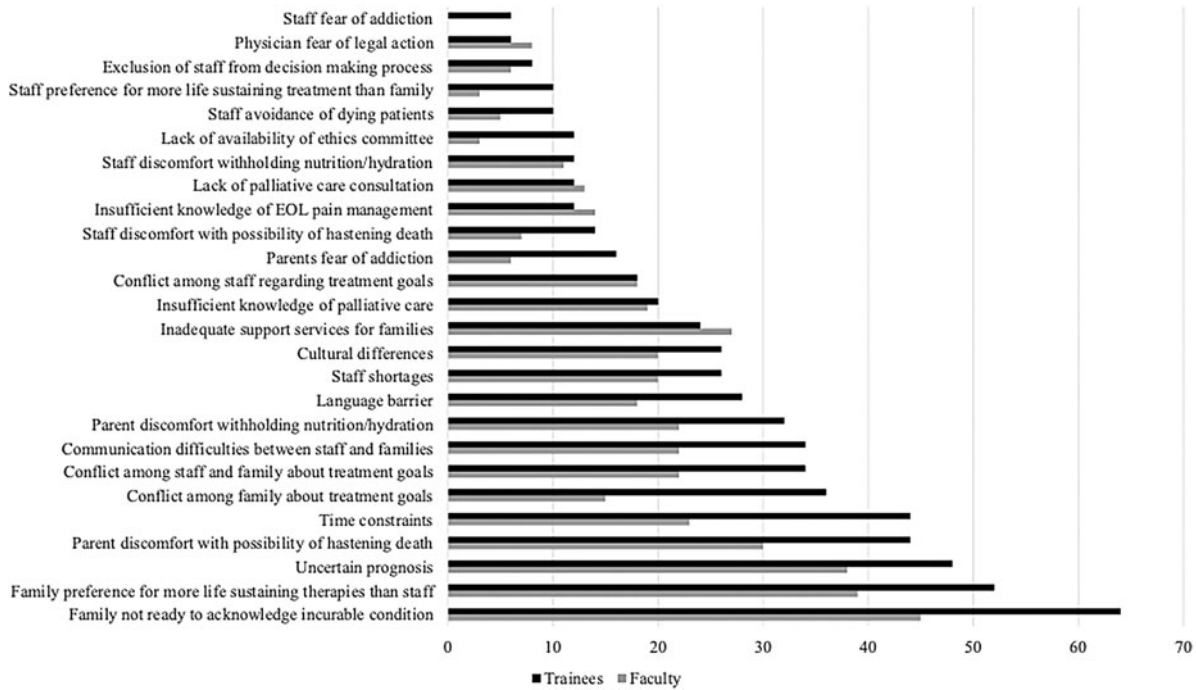


FIG. 1. Trainees versus faculty physician barriers occurring always or frequently.

Discussion

This study examining palliative care across two pediatric centers may suggest that trainees and faculty physicians believe that barriers related to their perception of family-driven factors impact palliative care provision for pediatric patients and their families more often than systemic or care team-driven barriers. Although trainees reported barriers generally occurring more often compared with faculty physicians, the identified barriers were similar and both groups desired more training in palliative and EOL care.

This study adds to existing literature on perceptions of barriers to palliative care for children with serious illness in pediatric hospitals. Studies suggest that acceptance of specialty PPC involvement has increased nationally, yet receipt of these ser-

vices and the provision of PPC for patients remain limited and varied in quality.^{8,19} Studies that examine nonspecialty palliative care are especially important because children with serious illness and their families should have access to these services regardless of the clinical setting in which they receive care.²⁰

Our study suggests that pediatric trainees and faculty physicians perceive barriers to palliative care as primarily influenced by their perceptions of family-driven factors, specifically the belief that a family has yet to acknowledge the incurability of their child’s condition and family preferences for more life-sustaining therapies. Although this may be the case in some circumstances, numerous studies suggest that families are aware of their child’s worsening health, want to discuss this with their child’s clinicians, and have varied goals of care that guide their treatment decisions for their child at end of life.^{21–24}

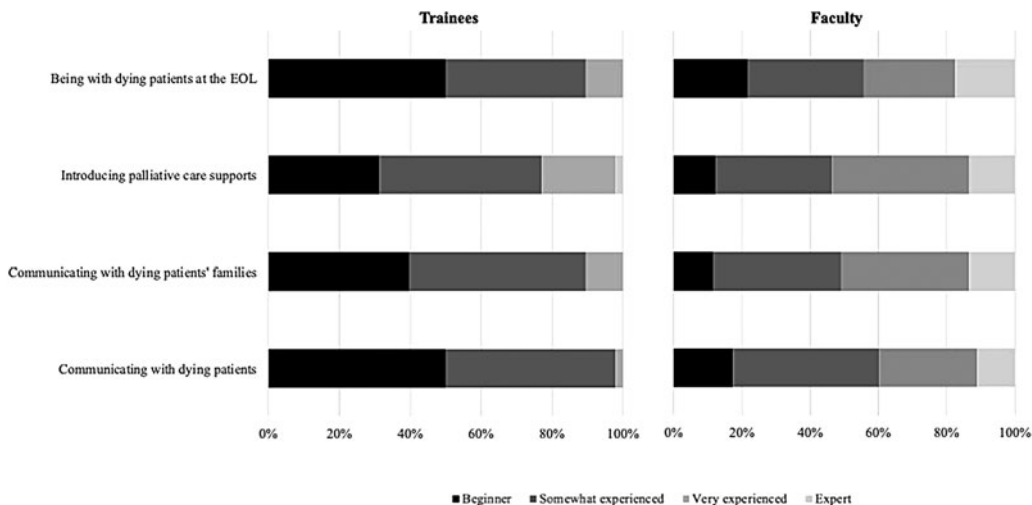


FIG. 2. Trainee and faculty physician confidence communicating with families.

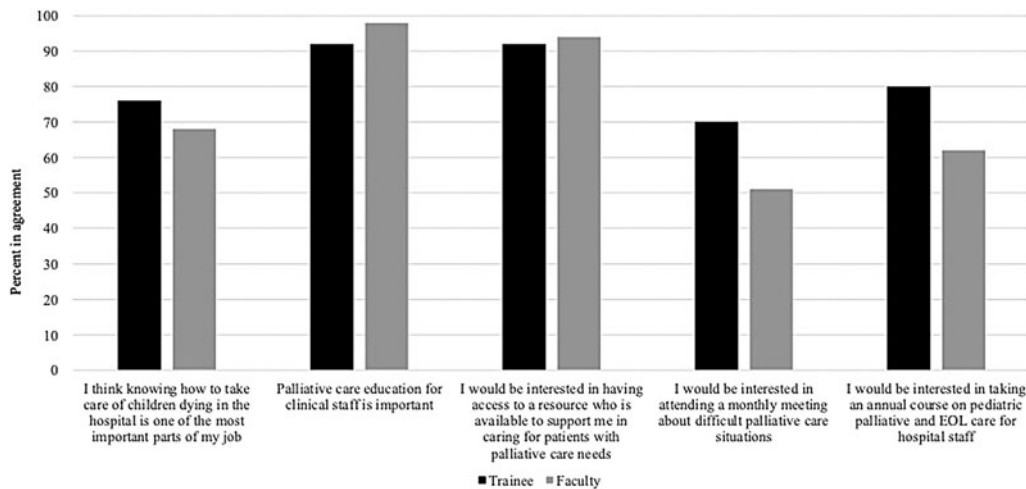


FIG. 3. Trainee versus faculty physician agreement with personal need for palliative care skills.

Clearly, there is work to be done to close the gap between families' beliefs and treatment preferences and their providers' perceptions of these issues. This can be done, in part, by improving training opportunities to promote skilled communication between care teams and families to align understanding and optimize palliative care support.

Additionally, we compared our findings with previous studies conducted at the same pediatric centers in 2008 and 2019 among clinicians (predominantly nurses) regarding barriers to palliative care.^{16,17} Many of the barriers persisted despite the time and programmatic changes at all the sites related to PPC. Specifically, four of the top five barriers were consistent across the studies, which similarly focused on family-related barriers to palliative care.^{16,17}

Additionally, uncertain prognosis was one of the commonly reported barriers that endured between studies. This is important because there has been substantial increase in access to genetic testing, improvement in imaging, and expansion in technical/surgical interventions between the previous two study time points and our study. While it may seem that these advances might solely alleviate prognostic uncertainty, there are many instances in which additional diagnostic information and interventional approaches can contribute to prognostic ambiguity.^{25–27}

It is likely that prognostic uncertainty will continue to be a concern among clinicians and families. Even though some diagnoses may find new therapies (e.g., spinal muscular atrophy), learning how to incorporate ambiguity and hold uncertainty in clinical outcomes and decision making as part of palliative care will continue to be essential to addressing this barrier.

Training and educational needs must also be addressed to better implement effective palliative care; trainees in particular voiced a desire to further develop their skills in various aspects of palliative care provision. Most commonly, we found that trainees desired additional preparation on being with and communicating with actively dying patients and their families, whereas they reported having more comfort working alongside patients' families in a longitudinal manner.

Additional educational emphasis on the lived experiences of children, adolescents, and their families at end of life and also how they prefer to receive palliative care updates and other forms of communication is needed.^{22,28,29} Studies that

evaluate patient-reported symptomatic improvement and perceived quality of care may offer ways of better understanding patient and family experiences to guide these training efforts.^{30–33}

Furthermore, it is essential that cultural humility should take priority in training and education in palliative care delivery.³⁴ Structural and institutional racism amplifies and perpetuates inequities in the delivery and experience of palliative care.^{35,36} Communication barriers, including inadequate language interpretation and even varied service offerings based on spoken language, were specifically cited by participants in this study as impacting the delivery of high-quality palliative care and meaningful EOL experiences.

These issues are likely to be even more pronounced at night, during emergency care situations, and in under-resourced hospital systems that may be less able to invest in reliable language interpretation personnel or technology or robust social work services during weekend and overnight hours. Furthermore, there is likely an underappreciation of the significance of individual biases that may limit open dialog between provider teams and patients/families, thus stunting the palliative care experience for all patients, especially those who are not White and primarily English speaking.^{34,37}

Finally, underutilization of multidisciplinary perspectives may further limit clinician awareness of the broad array of issues concerning patients at the end of life.^{38,39} Given well-documented research about the power dynamics inherently involved in medicine, it is critical to facilitate increasing individual awareness about making space for patients/families to state their priorities for EOL goals of care.

This should be paired with additional systemic changes that provide funding and resources for this type of excellence in clinical care—funding and resources that are required for the implementation of primary and secondary palliative care and also for continuing education and training in these fields at all training levels.

There is an ongoing need for additional research and nuanced training around cultural considerations, communication, and decision making in diverse patient populations to positively impact receipt of palliative care for all children and their families experiencing serious illness.^{40–44}

TABLE 2. QUOTES FROM TRAINEES AND FACULTY PHYSICIANS

Theme/subthemes	Trainees	Faculty physicians
<p>Facilitated palliative care provision and limited barriers: Anticipating and clarifying EOL plans in an iterative manner Fostering trust and connection with staff and families Family being able to be with their child at end of life</p>	<p>A teenager with autism who developed severe myocarditis and heart failure. The treatment would be transplant, but his family decided that they did not want to move forward with the transplant process given what was important to him and his quality of life. It was memorable because the parents made a clear, caring, and well-supported decision for their son.</p> <p>The relationships that were developed over time with the family and how as their goals of care evolved, we were able to walk that journey alongside them.</p> <p>Watching a patient who I initially was part of diagnosis for cancer worsening over 2 years in residency. Prior to death, he was frail, memory was weak, and physically couldn't move. However, still invited me to watch [basketball] in his room that season. Despite all he had been through, there was a connection there that has stuck with me for years.</p> <p>I was the fellow administering medications for comfort during a compassionate removal of a tracheostomy at the end of this patient's life. .. I remember his dad holding him and rocking him as he sang prayers over him as he passed. It was the most peaceful and beautiful thing I had ever seen.</p>	<p>Getting to know a child and his family as they realized he was at the end of life and building trust so that when he died, we had a human connection beyond the doctor-patient connection that alleviated suffering for both of us in a meaningful way. There was a fabulous interdisciplinary team addressing prognosis and ultimately the death. We had numerous meetings with the family and whole team. The family was accepting of the sad ultimate withdrawal of [life] support. The patient had lived 2 years following the diagnosis of incurable [cancer] and only came inpatient the day before she died with clear plans for palliative care. She was allowed to drink chocolate milk despite aspiration risk and died peacefully surrounded by her parents and the kind of support they wanted from our inpatient staff (nursing physical presence, noninvasive oxygen support, interpreter services). While they didn't want their daughter to die of course, this was a "good death" because they were able to choose the kinds of support they wanted, and there was remarkably less stress (both in staff and from parents, which is probably related as it is hard for staff not to reflect parent stress) than usual hospital deaths. I feel that it was a privilege to have been there.</p>
<p>Diminished efficacy of palliative care and acted as barriers: Uncertainty and/or rapid decline in the child's health Limited cultural diversity of providers Family and staff distress about conflicting treatment goals Inadequate resources, planning, and communication within teams to address EOL events Inconsistent palliative care definition</p>	<p>I am currently taking care of a patient. .. we do not know the prognosis, we do not know what she has, and therefore it has been very difficult to give parents any sort of answers, to understand how much hope we should or should not have, and to better understand if we are doing enough, which just eats away at me every day.</p> <p>My most memorable experience was in the NICU where palliative was consulted early in the pregnancy in prep for early demise immediately after birth. The baby lived to be placed in hospice; however, the staff particularly nursing were uncomfortable moving to comfort care and not providing surgical correction as the baby could have lived possibly to 1-2 years. But family choose to [have] no more interventions.</p>	<p>[My] most memorable distressing experience was an infant with short gut whose parents elected letting her die, instead of pursuing long-term TPN. The child was otherwise healthy. Still distressed by this. Ethics consulted and felt it was within the parents' right to make this decision.</p> <p>Overall feel very well supported by palliative care at our hospital, but would like to have more tools in my everyday practice that I can deploy myself.</p> <p>Patient had been DNR since she was born—yet parents had not been prepared for her death at age 2.5 years. [It] was traumatic and harmful for the family and staff—it was as if the palliative care team was following, but not really present, because of so many handoffs. There was no preparation for her death—there were many things to do in</p>

(continued)

TABLE 2. (CONTINUED)

<i>Theme/subthemes</i>	<i>Trainees</i>	<i>Faculty physicians</i>
	I had a patient who was on maximum support for days and was clinically worsening; I communicated frequently with the family through an interpreter multiple times/day. What made this case more challenging was that the siblings were never able to come in to meet their sibling before his death due to COVID restrictions—even though another family was able to have 10+ family members present at bedside for a patient who was eligible to donate organs. It struck me as being discriminatory due to one family not speaking English, and I am still mad about it and trying to make sure this never happens again.	terms of calling the funeral home, arranging transport, honoring cultural decisions—it was the opposite of thoughtful planning, instead the palliative care was passive and performative. As an adolescent medicine attending, we frequently consult palliative care for control of symptoms. We frequently struggle with patients who are refractory to care, particularly how to support young adults who have capacity, but refuse treatment. Some transition to a “palliative care” approach [could be helpful], but it is unclear what this means and is inconsistently applied.

DNR, do not resuscitate; EOL, end-of-life; NICU, neonatal intensive care unit; PICU, pediatric intensive care unit; TPN, total parenteral nutrition.

Limitations

There are several limitations to this study. The sample size was small and the response rate was low, limiting generalizability. The study included three pediatric hospitals in two pediatric centers in the western United States with different resources related to EOL care and PPC. There was likely existing variability in palliative care services and education at each of the sites, especially noting that three different health care systems were involved at the outset of this study with two centers merging during the study's completion, and so a direct comparison of trainee and faculty physician perspectives and resources was not feasible.

Additionally, the response rate of faculty attendings was greater than that of trainees and thus the results are more representative of the experience of faculty physicians at these sites. We also had a limited number of critical care specialties listed on our survey, limiting our ability to explore differences in opinion about barriers between specialty groups.

We also did not ask study participants to consider a specific time frame of practice when responding to survey items, which therefore may reflect residual attitudes about and/or experiences with palliative care that may be less relevant today. There may have also been a social desirability bias given that this study was conducted by attending palliative care and resident trainee researchers.

Finally, survey items were based on previous studies, which may have limited our ability to collect more contemporary information about persistent barriers to palliative care.

Despite these limitations, this study adds important information about current perspectives of trainees and faculty physicians. Open-ended responses gave participants the opportunity to share more about barriers they have experienced at these sites, which still serve to contribute additional breadth and depth to ongoing conversations across the country about improving palliative care for children with serious illness and their families.

Conclusions

This study examining palliative care across two pediatric centers suggests that trainees and faculty physicians perceive family-related barriers as being one of the more substantial sources of limited PPC engagement. Trainees reported barriers as generally occurring more often compared with faculty physicians. These barriers were similar to previous studies examining the perspectives of clinicians in pediatric centers. Both groups expressed a desire for increased opportunities for training in palliative care principles.

Future research should examine more family-centered and culturally based interventions that may help connect providers' discomfort in eliciting family input with prior research showing families' desire for increased communication. This may further participation in the EOL and goals of care processes that diminish persistent barriers to palliative care for pediatric patients and their families.

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Authors' Contributions

A.L. was involved in conceptualization (supporting), methodology (equal), investigation (lead), writing (original draft, review and editing) (supporting), and project administration (lead). P.A.W. was involved in investigation (supporting) and writing (original draft, review and editing) (supporting). A.H.F. was involved in investigation (supporting), data curation (lead), and writing (original draft, review and editing) (supporting). E.L. and P.M. were involved in writing (review and editing) (supporting). A.K.A. was involved in conceptualization (lead), methodology (equal), investigation (lead), formal analysis (equal), writing (review and editing) (supporting), and supervision (equal). J.F.B. was involved in methodology

(equal), formal analysis (lead), writing (original draft, review and editing) (lead), data curation (lead), visualization (lead), project administration, and supervision (equal).

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Author Disclosure Statement

No competing financial interests exist.

Supplementary Material

Supplementary Data S1

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Address correspondence to:

Alyssa Levine, MD

Department of Pediatrics

University of California, San Francisco

550 16th Street

San Francisco, CA 94158

USA

E-mail: alyssarebecca.levine@ucsf.edu