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Pediatric Oncology Provider Perceptions of a Pediatric Palliative Care Service: The Influence of Emotional Esteem and Emotional Labor

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Abstract

Context—Pediatric palliative care consults for children with cancer often occur late in the course of disease and close to death, when earlier involvement would reduce suffering. The perceptions that pediatric oncology providers hold about the pediatric palliative care service (PPCS) may shape referral patterns.

Objective—To explore how pediatric oncology providers at one institution perceived the hospital's PPCS and the way these perceptions may influence the timing of consultation.

Methods—We conducted semi-structured qualitative interviews with pediatric oncology providers at a large children's hospital. Interviews were audio recorded, transcribed and analyzed by two coders using a modified grounded theory approach.

Results—We interviewed 16 providers (10 physicians, 1 nurse practitioner, 2 social workers, 2 psychologists and 1 child life specialist). Three core perceptions emerged: (1) the PPCS offers a diverse range of valuable contributions to the care of children with advancing cancer; (2) providers held favorable opinions about the PPCS due to positive interactions with individual palliative care

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The authors have nothing to disclose.

specialists deemed extraordinarily emotionally skilled; and (3) there is considerable emotional labor involved in calling a PPCS consult that serves as a barrier to early initiation.

Conclusion—The pediatric oncology providers in our study held a highly favorable opinion about their institution’s PPCS and agreed that early consultation is ideal. However, they also described that formally consulting PPCS is extremely difficult because of what the PPCS symbolizes to families and the emotional labor that the provider must manage in introducing them. Interventions to encourage the early initiation of palliative care in this population may benefit from a focus on the emotional experiences of providers.

Keywords

Pediatric palliative care service; oncology; pediatrics; palliative care consultation; qualitative methods

Introduction

Children with advancing cancer frequently experience considerable symptoms and suffering during the end of life.^{1–4} Many parents of children who die of cancer report wishing that they had received more support and palliative care during their child’s illness.^{5–7} Some report never discussing end of life treatment with clinicians or regretting cancer treatments their child received at the end of life,⁸ while others report wishing that clinicians had better prepared them for the possibility of their child’s death.⁹ Pediatric oncology patients have been shown to benefit from the early involvement of palliative care providers, who can significantly improve quality of life and decrease a child’s suffering from pain and dyspnea.^{10–12} Yet, pediatric palliative care consults often occur late in the course of the disease and close to the child’s death.¹³ One study examined consults among children who died of cancer and found that while most were referred to palliative care, the majority occurred after the first (40%) or multiple (18%) relapses.¹⁴

The late involvement of palliative care may happen because pediatric oncologists are unfamiliar with or have a limited understanding of palliative care,^{15,16} equate involving palliative care with a failure on their part,¹⁷ or are too optimistic about the possibility of curing a patient.¹⁸ Much of the work on how clinicians think about palliative care and the barriers to early integration for patients with cancer has been conducted in adult oncology.^{19–22} There is scant research on the perceptions of pediatric oncology providers towards secondary pediatric palliative care services (PPCSs).

As the presence of PPCSs becomes more common in children’s hospitals throughout the United States,²³ and as new programs are developed,²⁴ there is a need to better understand how specific “end users” of the PPCS perceive it. Given the relatively late involvement of PPCSs in the care of children with advancing cancer, understanding pediatric oncology provider perceptions can also generate valuable information on referral timing for this patient population. Our objective in this study was to explore how pediatric oncology providers at one institution perceived the hospital’s PPCS and the way these perceptions may influence the timing of consultation.

Methods

Design, Sample and Recruitment

This article reports on results from a qualitative interview study that was conducted within the context of our team's work designing the Confronting Adversity through Regoaling Engagement (CARE) Discussions and Conversations intervention at the Children's Hospital of Philadelphia (CHOP). In the first phase of this study, we conducted a qualitative interview study to better understand the barriers and facilitators to introducing palliative care for children with advancing cancer. Semi-structured interviews were conducted with oncology providers (physicians, nurse practitioners, psychologists, social workers and child life staff) from the neuro-oncology, bone marrow transplant and solid tumor teams by a medical sociologist. Bedside nurses were excluded from this study because they were not included in the CARE intervention. Providers who had consented to participate in the CARE intervention were recruited to participate in an interview by the medical sociologist via email. A maximum of 3 recruitment emails were sent per respondent. Our protocol was approved by the CHOP Institutional Review Board and verbal informed consent was obtained from all research subjects.

The interview guides contained a subset of questions about CHOP's Pediatric Advanced Care Team (PACT). Founded in 2003, PACT is dedicated to relieving suffering and improving the quality of life of children living with life-limiting conditions and their families. The PACT consult service is available at all times, and can be requested by patients, families, or clinicians. PACT is a multidisciplinary team that includes physicians from diverse pediatric subspecialties, nurse coordinators, social workers, child life specialists, bereavement counselors, psychologists, and chaplains.²⁵

Data Collection

We developed our interview guide based on a review of the literature and conversations with the interdisciplinary CARE study team, which includes researchers with expertise in pediatric palliative care, medical ethics, nursing, oncology, social psychology and sociology. Questions were designed to be open-ended and to ensure that the prompts were not leading. See Table 1 for the subset of questions designed to elicit perceptions of PACT. Interviews were conducted in-person at a time and in a place of the respondent's choosing. The medical sociologist conducted all of the interviews and utilized the same interview guide across respondents, probing where necessary to encourage respondents to elaborate on their answers. All interviews were, with permission, recorded. Prior to the start of the interview, after informed consent was obtained, the respondent was told that PACT team members would not be made aware who chose to participate, nor would they be given access to identifiable data. Interviews were conducted until thematic saturation was achieved, which occurred after 8 interviews with a mix of physician and non-physician respondents.

Data Analysis

All audio files were transcribed and uploaded to QSR NVivo 11 qualitative data analysis software immediately upon completion of the interview. The medical sociologist monitored for thematic saturation during the data collection phase by reviewing each transcript closely

and making note of recurrent themes in each domain of the interview guide.²⁶ At the conclusion of data collection, the transcripts were independently analyzed using a modified grounded theory approach by two coders – the medical sociologist (JES) and a research assistant (TS). Themes and patterns in the text were systematically identified in a two-stage process. First, all transcripts were read in a process of open coding, capturing and defining salient themes that emerged inductively from the data. All codes were discussed by the analysts in weekly meetings and clearly defined. Disagreements were resolved by consensus and consultation with the larger CARE research team. Second, after the preliminary code list was developed, we reviewed all transcripts line by line to manually assign codes to passages of text. Inter-coder agreement was periodically assessed during weekly coding meetings and discrepancies were resolved through review of the coding schema. The results we present here are based on a sub analysis of 5 codes related to PACT, defined in Table 2.

Results

We recruited 42 pediatric oncology providers to participate in an interview and enrolled 16. The majority of non-respondents who returned our recruitment email declined due to scheduling constraints. Table 3 provides detail on the characteristics of our interview respondents. The majority (62.5%) were physicians. All interviews were conducted in person and ranged in length from 28–84 minutes.

Diverse Valuable Contributions of the PPCS

Our respondents had a highly favorable opinion of PACT and felt that PACT's early involvement in the care of children with advancing cancer is beneficial. As one nurse practitioner states:

“I think [PACT] is great. They're a great resource. They're always happy to come see a new patient. They are very involved in patients they are consulted on. And if the patient is in the hospital, they come by every day. They come and find us to communicate what they think we should be doing. They're great.”

Our respondents articulated a diversity of ways in which PACT improved the quality of the care delivered to these children. In addition to widely recognized expertise in pain and symptom management (see Table 4, **Quotation #1 [Q#1]**), our respondents identified domains of valuable work that PACT performs for families including facilitating the transition from hospital to home at end of life by navigating the “administrative subculture” surrounding this transfer (**Q#2**), being easily accessible to families for support via phone around the clock (**Q#3**), providing parents with reassurance (**Q#4**), offering psychosocial support to the child's siblings (**Q#5**) and helping families to clarify goals (**Q#6**).

Emotional Esteem of PPCS Members

In expounding on the value of PACT, many of our respondents went beyond listing specific services. They expressed a high level of esteem for the emotional skills exhibited by the members of PACT at times almost to the point of veneration. Respondents spoke of feeling moved upon witnessing PACT members at work, as if they were watching a performance (**Q#7**) Multiple respondents described the way that PACT team members communicate with

families as “beautiful.” Some became visibly emotional when they talked about how affected they were by past experiences working with PACT members, as is exhibited in this interview:

“But I can tell you there was one case where PACT was involved but I was still the primary physician. It was a single mom. This was her only child. This was a family that was really doing everything to keep this poor kid alive. I did a lot of home visits with this family. I did home visits with [NAME2]. I saw the work that [NAME2] did [*respondent’s eyes well with tears and her voice breaks*]. And I get emotional even thinking about it, because it was amazing. She just brought this mom around in a way that none of us could ever do. [*Respondent pauses and cries*]. Sorry.” (Physician)

Throughout our interviews we found that, when we asked respondents about PACT, instead of speaking about the dynamics of the service as a whole they discussed the actions of individual providers. As one physician states:

“[PACT] is so many things. I’ve never seen anyone as good at thinking proactively about symptom management as [NAME2], ever. She is so strong about ‘what are we going to do?’ That message comes so strongly from her that the families love it because what they want is someone to help them. Some of the other PACT people are the most lovely people. Their social skills are tremendous. They’re so compassionate. I get to observe a variety of PACT people. The business-like way that [NAME2] does stuff gives families so much confidence. This group isn’t just to talk about your feelings. It’s value added to my medical care. At least as I watch it, I feel that gets the team so much further. And I see [NAME3] and [NAME4] doing this too.”

Our respondents identified features of PACT clinician’s interpersonal styles that they admired, including projections of confidence, patience and social skill. PACT members were described as “special” and “unique” people (Q#8).

In addition to expressing esteem for the skills of individual PACT clinicians, many respondents described how PACT helps them manage the time consuming and emotionally difficult work of caring for very sick patients and their families. As one physician explains:

“The PACT team, and this is one of the most valuable things, they have the time to sit for an hour, hear the fears, hear the problems, partner with that family, cry with that family. I’ve got 17 other patients to see. You got seven minutes. But I’m an inpatient attending. I don’t have time. I the try to make the time for the meeting where we talk about something specific, but on a daily basis? You’re not getting that from me. And I cannot deliver that to you in an effective way. The PACT team can absolutely do that and that is immensely valuable because they are providing something that I should but can’t.”

Other respondents reported “outsourcing the emotional burden” of caring for dying children onto PACT either because they do not feel they have time (Q#9) or to help them care for patients who present with a poor prognosis in order to keep their emotional distance (Q#10).

Emotional Labor Involved in Obtaining a PPCS Consultation

Although our respondents acknowledged the valuable contributions that PACT could offer and lauded their emotional skills, they described nuanced challenges that served as a barrier to early consultation. Most respondents suggested that the reason PACT is not consulted earlier is because they perceive that families are not ready for them (Q#11). Our respondents almost universally explained that even hearing the PACT name was “triggering” for families (Q#12) and could cause parents to have an emotional shutdown (Q#13). As one social worker explained:

“I think when somebody asks what the PACT team is, if you say, ‘This is our palliative care team,’ that is a – ‘I’m sorry, what? You said that we have a plan for my child, and this is what we hope for, and now you’re saying you’re going to bring in a –’ I just think the association of the word palliative, particularly with families who’ve had experience, maybe like grandma or grandpa – somebody went home on hospice – I think that is an immediate trigger, just the word.”

Numerous respondents explained that they believed families hear “palliative” as “death” and once this language is used the conversation is derailed (Q#14). Multiple respondents reported that parents of children who had been cared for at the hospital for a long time talked amongst each other and referred to PACT as “the death team.” The strong association of PACT with end of life care was echoed our respondent’s confusion over what PACT stood for. A number thought the “P” in PACT referred to “palliative,” even though the “P” actually stands for “pediatric” (Q#15).

For our physician respondents, formally consulting PACT was perceived as a difficult thing to do because of what the consult symbolized. Introducing PACT to a family requires that the clinician perform intense emotional labor, as one respondent explains:

“I think all death, all end of life, all discussions of this nature take a toll. They take a lot of time. It’s an investment. If you’re going to sit with a family and discuss the merits, the benefits, why we think it’s important, you have to first explain where we’re at. Why am I telling you this today? So it is recapping everything, where we’ve been, what we’re going through, why I’m nervous today, why I think we need to get another team involved.” (Physician)

While the majority of our physician respondents explained that PACT is called in later than is ideal because families are not ready, a few admitted that this delay may also be that the pediatric oncology providers themselves are hesitant. As one physician explains:

“We say it is the family [who isn’t ready for PACT] but it’s a little bit us. We say ‘They can’t hear it. They’re not ready.’ Which sometimes means ‘I can’t hear it. I’m not ready,’ honestly.”

Other respondents described delaying the introduction of PACT for patients with whom they had a particularly close relationship because they feared alienating the family (Q#16). Our non-physician respondents reported similar observations about their physician colleagues, whom they perceived made the ultimate decision about when to formally consult PACT. One

social worker describes how she engages her reluctant physician colleagues to consult PACT earlier by promoting the psychosocial benefits offered by the service (Q#17).

Considering a PACT consult is emotionally difficult for physicians in a way that consults with other subspecialists are not. One physician who had come from an institution without a PPCS said the following:

“Before I came here, I was at a smaller institution. There was no PACT team. So, the oncologist did the palliative care. Here there is a distinct consult that happens. In your mind you bring another service in. It’s a really very clear shift from curative thinking to palliative thinking. Something about consulting the PACT team crystallizes that in a way that was different for me than it was when I was at an institution that didn’t have a formal PACT team. I think that process was more evolution than revolution in your thinking.”

Having a patient and family meet a whole new set of providers makes the potential shift in goals abundantly clear and unequivocal. All respondents were asked if they perceived that there was ever a downside to involving PACT. The emotional weight of a PACT consult was echoed in their answers. As one physician explained:

“So there is mostly not a downside to involving PACT, with the exception being that family where your relationship is tenuous and this offer is so upsetting that it just [further] impairs your relationship with them.”

Respondents largely felt that there were no downsides, unless their relationship with the family was strained or the family was felt to not be emotionally ready (Q#18).

Discussion

In this qualitative study investigating how pediatric oncology providers at one hospital perceive their institution’s PPCS we found that respondents held an overwhelmingly favorable opinion of the PPCS based on interactions they had had with individual team members deemed extraordinarily emotionally skilled. While our respondents perceived the PPCS to provide a diverse array of highly valuable contributions to the care of children with advancing cancer and expertise in managing the emotional challenges of caring for these children, the act of formally consulting the PPCS was perceived to be accompanied by considerable emotional labor for the primary team, which served as a barrier to early referral. Our study illuminates the nuanced ways in which the perceptions held by pediatric oncology providers about the PPCS may shape the timing of secondary palliative care consultations. These insights may help in the development of novel strategies to facilitate the earlier involvement of the PPCS.

This study confirms the findings of previous research in several ways. First, our analysis shows that pediatric oncology providers express reluctance and uncertainty about when is an appropriate time to consult the PPCS. Previous research has demonstrated that children with advancing cancer are referred to palliative care late in the course of their disease.^{13,14} Although there is little research on the perceptions of pediatric oncology providers, one study found this reluctance stems from concern about an overlap in roles between the

primary oncology team and the PPCS because oncologists see themselves as already providing palliative care, a sense that the philosophy of palliative care is inconsistent with cure-directed therapy, and a belief that introducing the PPCS too early could lead to increased parent anxiety.¹⁸

Second, we found that when respondents were asked about their perceptions of the hospital's PPCS they talked extensively and admiringly about the behaviors of individual palliative care clinicians. They cited these clinicians by name and described them as being universally well-respected and almost magically skilled at what they do. Previous research has demonstrated that oncologists hold particularly positive perceptions of palliative care nurse practitioners whom they describe using similar superlatives to those that our respondents used.¹⁹

The findings of our study go beyond what has previously been reported by identifying novel insights into the way that pediatric oncology providers conceptualize their own work and the work of the PPCS. We found that the act of calling a PPCS consult is difficult because broaching the topic of palliative care requires considerable emotional labor on the part of the provider. A PPCS consult is symbolic and emotionally freighted in a way that consultation with other subspecialties is not. Pursuing a PPCS consultation makes real for the provider and the family a possibility that has always been lurking in the background but has not yet been articulated: the child is dying. While our respondents explicitly describe they are reluctant to consult the PPCS because they do not want to upset families, their nuanced answers in our interviews revealed that consulting PPCS is difficult for them as well.

Emotional labor is useful for interpreting this finding. In sociology, emotional labor is conceived of as the process that individual workers go through to manage their own displays of emotion in order to project a desired image to clients.^{27,28} For physicians, this regulation of emotion is intended to present a professional demeanor to the patient, the patient's family and one's colleagues.²⁹ Emotional labor self-regulation may entail suppressing one's own strong emotional reactions to situations encountered at work to conform to professional norms. Emotional labor can have negative impacts on the worker and has been linked to decreased job satisfaction and burnout.^{30,31} In the specific clinical scenario of potentially consulting the PPCS, pediatric oncology providers confront remarkable amounts of emotional labor, regarding both the provider's personal reactions to a child's progressive disease, and the provider's reaction to the family's reaction. The prospect of an excessive amount of emotional labor may inhibit early consultation of the PPCS.

In this context of emotional labor, pediatric oncology providers' perceptions that PPCS team members possess "special" emotional skills worthy of esteem may both facilitate and – ironically – hinder PPCS consultation. On the one hand, this esteem may address and offset concerns about the emotional reactions that requesting a PPCS consultation might engender in the patient or family. On the other hand, by conceiving of the palliative care clinician as possessing a "special" set of skills that set them apart, oncologists may distance themselves from aspects of the emotional labor of caring for patients with advancing cancer, and opportunities to nurture and improve their own emotional capacity to address the challenges

posed by advancing pediatric cancer, thereby delaying discussions about initiating palliative care.

Our study has four principal limitations. First, because we utilized a qualitative design at a single site, our findings have limited generalizability to settings beyond the hospital where we conducted this study. Second, our sample may be biased: the oncology providers who agreed to be interviewed may have possessed systematically different characteristics that influenced their decision to participate and shaped their perceptions of the PPCS compared to those not interviewed. Third, half of respondents in our study were attending physicians, and another 2 respondents were fellows. Despite our best efforts, we were unable to recruit a substantial amount of nurse practitioners, social workers or other types of healthcare professionals into the study. As such, we were constrained in our ability to systematically analyze variation in the perceptions of the PPCS by occupational role. Nevertheless, the data from our non-physician respondents provided valuable insight that confirmed and expanded upon what our physician respondents reported. Additional research is needed to understand variation in perception by occupational role. Fourth, our sample size is small. While we only recruited 16 respondents to participate in an interview, we reached thematic saturation on the focused nature of the research question answered in this manuscript quickly.

Despite these limitations, our findings suggest possible mechanisms by which perceptions shape decision making about the timing of referral to palliative care for children with advancing cancer. We need a better understanding of the way pediatric oncology clinicians' emotional management skills influence the timing of requesting PPCS consultations. Furthermore, we need better specification of the particular skills that PPCS clinicians exhibit that are esteemed by the pediatric oncology team members so that these skills can be more broadly taught.

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Table 1

Interview Questions About PACT

In your own words, what do you think PACT does?
What do you think PACT offers to patients and families?
What do you think PACT offers to you?
How does PACT impact the kind of care you are able to provide?
Can you describe, generally, what the threshold is over which you involve PACT in a patient case?
Do you perceive that there is ever a downside in involving PACT in a patient's care?

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Table 2

PACT Code Definitions

Code	Definition
Beneficial PACT Involvement	when PACT involvement is seen to have been helpful or beneficial to a patient, family, or medical team
History of PACT	a discussion of the evolution of PACT at CHOP, how palliative care in oncology at the hospital has evolved
Nonbeneficial PACT Involvement	when PACT involvement is seen to have been harmful or not beneficial to a patient, family, or medical team
Reasons to Involve PACT	justifications that people give for why they get PACT involved in the care of a patient
Timing of PACT Involvement	a discussion of the timing of consulting PACT and the factors that influence it

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Table 3

Characteristics of Interview Respondents, n = 16

Characteristic	n (%)
Professional Role	
Attending Physician	8 (50)
Fellow Physician	2 (12.5)
Nurse Practitioner	1 (6.3)
Social Worker	2 (12.5)
Psychologist	2 (12.5)
Child Life Specialist	1 (6.3)
Area of Practice	
Neuro-oncology	3 (18.8)
Bone marrow transplant	4 (25)
Solid tumor	4 (25)
General oncology	5 (31.3)
Years Worked at CHOP	
0–4 years	4 (25)
5–10 years	6 (37.5)
11–15 years	4 (25)
16 + years	2 (12.5)
Gender	
Female	12 (75)
Male	4 (25)

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Table 4

Themes and Illustrative Quotations

Theme	Subtheme	Illustrative Quotation
Diverse Range of Valuable Contributions	Pain and symptom management	Q#1. "Sometimes we have patients present with such severe pain or side effects from the location of the tumor, there is a role for the palliative care team to be involved whether it is 'help us manage this patient's pain' or they have expertise in using methadone and we don't use methadone all the time, so 'do you think this would be effective for this patient to get methadone?' We'll get them involved based on symptom management." – <i>Nurse Practitioner</i>
	Expertise in administrative and logistical issues in providing end of life care	Q#2. "There's a whole kind of administrative subculture on how to do this – how to manage the homecare agencies, how do you order a specialty bed – all the stuff that we don't know how to do because we don't do it all the time. To have a team that does it all the time, it just makes it easier to have them do it because it saves a lot of effort and a lot of mistakes." – <i>Physician</i>
	Continuous support to families	Q#3. "Something as simple as just communication with hospice and families. Recognizing that I don't want to be on call and available by phone 24/7 and knowing that someone's always on call. That communication aspect is really important to me in maintaining my sanity and work-life balance." – <i>Physician</i>
	Reassurance to parents about what to expect at end of life	Q#4. "I think they offer support more than anything and just reassurance that that patient is not gonna die a painful death. And I feel like I've never heard anything but amazingly wonderful positive stories about them. So it's kind of reassurance that we're gonna take care of you and your child at home and we're not gonna let anything bad happen. And experience, that they've done this before." – <i>Child Life</i>
	Psychosocial support to siblings	Q#5. "There is psychosocial supports within PACT that can help the family. They have child life and they have social work services and so that is good for working with the siblings in the home. They will do home visits." – <i>Social Worker</i>
	Clarification of goals	Q#6. "And so, I think engaging the PACT team and sort of – at least bringing in a parallel palliative approach – because I don't always think it's either or, right? – was about, OK, we need to clarify her goals, and it would, I think, help to have the kind of multidisciplinary expertise that the PACT team brings in." – <i>Physician</i>
The Emotional Esteem of PACT Members	Awe in watching PACT work	Q#7. "You watch someone like [NAME1] talk to a family. She does it so beautifully. It's like a performance. You just go 'wow. That was really great.'" – <i>Physician</i> Q#8. "I would say that how a certain service of the hospital is viewed is how the people who populate that service are viewed...And so I will say [NAME3] is universally admired. And so that spreads to everything that she touches is golden and I would be shocked if you could find a person who would say that the PACT team isn't kind, well-run, efficient, gets the job done...[NAME3] is the brand, if you will...She is the face for us of those services, and she is always gracious, and thoughtful, and gets the job done, and families love her. And maybe this is stereotyping, but I think the kind of person who would choose to do death and dying with children would have to be a unique person." – <i>Physician</i>
	Outsourcing the emotional labor to PACT	Q#9. "The PACT team, and this is one of the most valuable things, they have the time to sit for an hour, hear the fears, hear the problems, partner with that family, cry with that family. I've got 17 other patients to see. You got seven minutes. But I'm an inpatient attending. I don't have the time. I try to make the time for the meeting where we talk about something specific, but on a daily basis? You're not getting that from me. And I cannot deliver that to you in an effective way. The PACT team can absolutely do that and that is immensely valuable because they are providing something that I should but can't." – <i>Physician</i> Q#10. "For a couple of my patients they [PACT] communicated more often with the family than I did, which I recognized after the kid died. I didn't do home visits with the family, which I've done before and still do. But they called the PACT phone more than they called oncology. I really think that was intentional on my part. I was just backing away. For patients that I know they have a terrible disease up front, I purposefully keep a little bit of distance. It doesn't impact the care that I give them but I feel I emotionally don't let myself get too involved." – <i>Physician</i>
Social and emotional labor involved in a PACT consult	Families are not ready for PACT	Q#11. "I wish families would accept PACT sooner. Because often it is not a matter of bringing up the concept, it's knowing that if I call at a certain point, the family is gonna reject PACT." – <i>Physician</i>
	The name PACT triggers an association with death and invoking it has emotional consequences	Q#12. "It is funny how when you describe what the PACT team does, families are very accepting of these roles. [But] when they ask you what PACT stands for, it falls apart." – <i>Physician</i> Q#13. "You fear that you would alienate the family and especially a family who is very much in denial that this patient is going to die, [gets] very upset by the conversation and says 'you think there's little hope for any more tumor directed therapy?' And then you go

Theme	Subtheme	Illustrative Quotation
		<p>back in and say 'actually we're going to bring in this team and they Google it and it means hospice to them.' –<i>Physician</i></p> <p>Q#14. “When a regular family hears the word palliative they just hear their kid is dying. That’s it. They can’t focus on anything else beyond that versus you have whatever time you have. What is going to be the most quality and impacting time to have? I can only imagine it is very hard to shift the conversation from ‘my child is dying’ to ‘how can I make life the best for the time remaining.’ that is massive. That cannot happen in one conversation.” - <i>Psychologist</i></p>
	Confusion about what the acronym PACT refers to	<p>Q# 15. “Respondent: The PACT team is an interesting name. It is very important that families know exactly what they are getting into. What does PACT stand for? Interviewer: Pediatric Advanced Care Team Respondent: I will tell you that everyone that you ask that to who doesn’t know what it stands for will be like ‘it’s palliative, something, something. The P is palliative for them. I didn’t even know what it actually stands for. I knew the advanced care part but I didn’t know the P was pediatric.” -<i>Psychologist</i></p>
	Physicians aren’t ready for PACT	<p>Q#16. “Although we all have the inherent feeling that [the patient’s] maybe not super long for this world because of the way – you know this is his second relapse. But his family is like in a totally different direction. And this is my primary patient, we email all the time and they tell me they love me and we’re like, I’m like part of the family. But I still haven’t gone there [consulted or introduced PACT] so I feel responsible for that too...It is hard to not alienate them, to be honest with them without alienating them.”-<i>Physician</i></p>
	Physicians sometimes need encouragement to consult PACT	<p>Q#17 “We were talking as a social work group that there’s some times we could probably drive the ship a little bit more than we do, particularly when we know that there’s psychosocial supports within PACT that can help the family...And so sometimes that’s an angle to get PACT involved but I think I need to kind of be at a point where I need to talk to the physician and say ‘Okay, maybe you don’t feel like they need PACT but this is what PACT can offer so why don’t we go this route?’”-<i>Social Worker</i></p>
	Bringing PACT in is risky if family not emotionally ready or have a tenuous relationship with them	<p>Q#18. “Interviewer: Do you ever perceive there is a downside in involving PACT in a patient’s case? Respondent: Only if they are not emotionally ready for it. Interviewer: What could happen in that case? Respondent: They just feel like the child is dead. They don’t understand that there is still time.” -<i>Physician</i></p>

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