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### Pediatric Oncology Providers Perceptions of Barriers and Facilitators to Early Integration of Pediatric Palliative Care

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#### Abstract

**Background**—Pediatric patients experience significant symptoms during cancer treatment. Symptom management is frequently inadequate. We studied perceptions of pediatric oncology care providers regarding early integration of palliative care (PC) for pediatric patients to identify barriers and facilitators that might assist in understanding how care could be improved.

**Procedures**—Pediatric oncology providers were recruited to participate in four focus groups. A proposal for early integration of a pediatric palliative care team (PPCT) was presented and followed by a facilitated discussion. Data were analytically categorized into themes by three independent coders using constant comparative analysis and crystallization techniques. A consensus approach was used to indentify final themes.

**Results**—Barriers to the proposed care model of early integration of a PPCT included provider role, conflicting philosophy, patient readiness and emotional influence and were more prevalent in the physician participants compared to nurse practitioner, nursing, and social work participants. Facilitators included patient eligibility, improved patient care, education, and evidence-based medicine. Though all participants were invested in providing optimal patient care, physician participants believed the current standard of care model is meeting the needs of patients and family, while the nurse practitioner, nursing, and social work participants working on the same healthcare team believed the proposed care model would improve the overall care of children diagnosed with cancer.

**Conclusions**—Differing perceptions among healthcare providers regarding the care of children with cancer suggest that team functioning could be improved. Avenues for pilot testing early integration of PC could provide useful information for a next study.

#### Keywords

Palliative care; Pediatric; Oncology; Perceptions; Barriers

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#### Introduction

Although supportive care is improving for pediatric oncology patients,<sup>1</sup> many children experience significant symptoms during cancer treatment and at end of life.<sup>2, 3</sup> In 2000, Wolfe et al. reported that 89% of parents whose child had died of cancer stated their child experienced "a lot" or "a great deal" of suffering from at least one symptom during the end of life.<sup>3</sup> Parents also reported that successful treatment of these symptoms occurred less than 30% of the time. In another study of children with cancer, uncontrolled suffering at end of life was more common among children undergoing stem cell transplant compared to those not receiving a transplant.<sup>2</sup> These observations may be a result of discordance between physicians' and parents' perceptions of symptoms in ill children.<sup>3</sup> A 2008 follow-up study<sup>1</sup> documented a greater emphasis on palliative care (PC) in children who died of cancer which correlated with better patient experiences, including less suffering and increased parental preparedness prior to their child's death.

In 2000, the American Academy of Pediatrics recommended pediatric palliative care (PCC) be integrated early on as part of care provided to children with life threatening conditions.<sup>4</sup> Despite these recommendations and evidence that supports the benefits of early integration of (PC), barriers to incorporating this service exist. These include concerns about uncertain prognosis, perceptions that families are not ready to acknowledge their child has a potentially incurable disease, and a lack of access to PC consultation.<sup>5</sup> Thompson, et al. surveyed pediatricians and found that almost half believed that PC is indicated only at the end of life when curative treatment is no longer a goal.<sup>6</sup> Three of four studies on when to introduce PC have been conducted with general pediatricians.<sup>5, 6, 7, 8</sup> To our knowledge, no research has focused specifically on perspectives of pediatric oncology providers. One study examined PC consultation among children who died from cancer and found that 40% of referrals took place after the first relapse, with 16% occurring within the first 30 days of diagnosis.<sup>9</sup> Our study investigated pediatric oncology providers' perceptions of barriers and facilitators to early integration of a pediatric palliative care team (PPCT) as a standard part of treatment for children with cancer.

#### Methods

#### **Participants and Procedures**

We conducted four focus groups with pediatric oncology providers at an academic children's hospital. The Institutional Review Board approved all study activities. Pediatric oncology providers included attendings, fellows, nurse practitioners, social workers and nurses. Exclusion criterion included unwillingness or inability to participate in a focus group session. Participants were recruited through written invitation and were consented electronically. Participants were divided into three groups: 1) physicians and fellows, 2) nurse practitioners and social workers, and 3) inpatient and outpatient nurses. This was done to take advantage of each group's specific expertise and how this might inform their perspectives, and to encourage willingness to honestly express viewpoints, which might not occur if hierarchical persuasion existed. Two focus groups were held with nurses to accommodate work schedules, for a total of four exploratory focus groups. We conducted two validation focus groups after initial analysis was performed to verify emergent themes based on selected exemplars to substantiate our findings. This additional step strengthened the findings by having participants affirm or clarify any discrepancies in our interpretation of emerging themes in the initial data set.

Prior to participation in the focus group, participants completed a demographic survey and clinical practice history, which asked about age, gender, profession, training completion

year, and years of clinical practice. At the beginning of each focus group, participants observed a 10-minute presentation by author TD outlining a proposed model for early integration of PC, including the study institution's indications for PC referral (Table I). Participants were then allowed to ask clarifying questions. Author PAC facilitated the rest of the focus group using an interview schedule (Supplemental Appendix) designed to elicit perspectives regarding early integration of palliative care in a neutral, non-leading way while using prompts to clarify or to delve more deeply into responses. The focus groups occurred between March and November 2011.

#### **Data Collection and Analyses**

Focus groups were audio recorded, de-identified and transcribed verbatim by an independent transcription service, and double-checked for accuracy. Resultant data files were loaded into NVivo qualitative analysis software v.8.0<sup>10</sup> for coding and analysis. The analytic approach used constant comparative analysis and immersion/crystallization, which involves: 1) independent identification and reflection of emerging themes, 2) creating a codebook, 3) merging codes into similar themes, and 4) using a consensus approach to identify final emerging themes. <sup>11–13</sup> Three authors (TD, EJF, JM) independently coded during the first immersion/crystallization cycle to develop a preliminary codebook. The codebook was refined as were themes and relationships among themes during the second immersion/ crystallization cycle until consensus was reached among the analytic team. At designated intervals, the focus group facilitator met with analysts to review, independently audit, and assess the validity of emerging findings. The goal of this approach was to group similar themes together while accounting for each unique code. Once the final codebook was agreed upon, investigators coded each subsequent transcript using discussion and eventual consensus.

#### Results

#### Demographics

Participants of initial focus groups included 15 physicians, seven nurse practitioners, two social workers, and nine inpatient and outpatient nurses. Of the original 15 physicians, 12 (80%) participated in the validation focus group. Four of the original five nurse practitioners (80%), both of the social workers, and two of the original nine nurses (22%) participated in the validation focus groups. Reasons for not participating in the validation groups included work schedule conflicts, which affected the nurses disproportionately, as well as providers who had since taken positions at other institutions.

The mean age of focus group participants was 41 years of age, with a range of 29–66, with twice as many females as male (Table II). The focus group data analysis identified four themes associated with barriers and five themes that served as facilitators of early integration of pediatric palliative care.

**Barriers**—Barrier themes included: 1) provider role, 2) conflicting philosophy, 3) patient readiness, and 4) emotional influence (Table III).

**Provider Role:** Participants in all provider groups reported concern about overlap in roles between the primary oncology team and the palliative care team. Physicians expressed views indicating patients' PC needs are already adequately addressed by the oncology team, which typically includes a primary physician, nurse and social worker. Both physicians and nurses raised concerns that having another team addressing aspects of PC might negatively affect the physician/patient/family relationship. One physician indicated the proposed early

integration care model could make the oncologist, "look bad." This comment resonated throughout the physician group.

Conversely, nurse practitioners and social workers indicated that patient needs are not adequately being met when palliative care is offered only when cure is no longer the goal. Despite recognizing the potential overlap in patient care by the oncology team and the PPCT, nurses also believed this model could better meet the complex needs of children with cancer compared to the current model. Among nurses and nurse practitioners, general consensus existed that patient symptoms, particularly psychosocial symptoms, contributed to lower quality of life and could benefit from more focused attention. The validation group confirmed this finding.

Participants in both validation focus groups identified the physicians' need to control aspects of patient care. Most physicians perceived treatment-related symptom management and discussions of diagnosis, prognosis, and treatment options as responsibilities of the treating physician alone. Although the PPCT was viewed as a subspecialty with specific expertise, a subset of physicians commented that consults from other subspecialists (e.g. pediatric nephrologists) are embraced more willingly than palliative care consults. Physicians also made a distinction between treatment-related symptoms and disease-related symptoms, indicating the oncology team could best manage the former, while the latter may or may not be best managed by the PPCT. In the validation group, physicians clarified the purpose of the PC consult within the first month of diagnosis as being for educational purposes only.

<u>Conflicting Philosophy:</u> Approximately half of the physician participants believed the purpose of PC is inconsistent with cure and only appropriate when cure is no longer the goal. Non-physician focus group participants did not share this belief. There was consensus among all participants in the latter group that PC was well suited for children who have a life threatening disease treated with curative intent. Concerns were expressed by many participants that introducing the PPCT in the first month of diagnosis could lead to additional parental anxiety, as the lay public often considers -palliative care- to be synonymous with -hospice care-. Changing the title of the PPCT to the "Supportive Care Team" or "Quality of Life Team" was proposed as a means of addressing misconceptions.

**Patient Readiness:** Given the complex information families must digest early in their child's diagnosis, nearly all participants expressed concern that introducing the PPCT early could lead to additional parental burden. Five of 10 attending physicians believed that PC is inconsistent with curative intent and emphasized that patients and families may not be ready for a PC consult during the diagnostic period. No attending physicians contradicted this perception in the initial focus group or the validation group. However, non-physician participants expressed that the anxiety caused by early integration of a PPCT would be far less than the anxiety experienced during relapse or disease progression. Overall, provider groups stated the early integration model places a burden on patient families. Introducing this model as standard of care was accepted by most participants as a means to alleviate potential anxiety a family might experience when meeting the PPCT.

**Emotional Influence:** Several providers, especially nurse practitioners, were concerned that primary oncologists' emotions influence patient care. This occurs when physicians' hope for cure, even when the prognosis is poor, may bias treatment decisions and how information regarding therapeutic options is relayed to patients and families. This emotional attachment and potential bias was perceived to intensify over time. Nurses noted that physicians tend to be overly optimistic when it comes to their own patients and speculated that the primary oncologist feels responsible for their patient's death and that fear of failure influences decisions. One nurse commented that even with enrollment in a phase I study, where the

Dalberg et al.

purpose of the study is to gain information about an investigational drug rather than cure the disease, physicians are often overly optimistic in information they provide about experimental drugs.

**Facilitators**—Major facilitator themes identified included: 1) patient eligibility and timing 2) improved patient care, 3) education, and 4) evidence-based medicine (Table IV).

**Patient Eligibility and Timing:** Physician participants indicated that patients with overall survival of <40 - 50% would likely benefit from early integration of PC. This perspective differed from all other participants who expressed concerns that presuming who would benefit from a PPCT based solely on prognosis would exclude some patients in need. Even if the prognosis is favorable, families may have difficulty coping with their child's cancer diagnosis. It was clear among all provider groups that the PPCT would be educating families at the initial consultation and at transition points (e.g., end of treatment, relapse), when anxiety may be higher. All providers agreed that the frequency of consultation would be most appropriate on an as needed basis determined by the primary oncologist.

**Improved Patient Care:** Non-physician participants were more receptive to integrating the PPCT within the first month of diagnosis for all children with cancer compared to physicians. Eight of 10 nurses and social workers believed early integration would address symptoms and suffering better than current practice. In the validation group this theme reached consensus among nurses. Nurses believed the PPCT role is currently underutilized and that patient needs during active treatment often go unmet. They noted that parents frequently bring concerns to them before they are discussed with other providers as nurses are more readily available and parents sometimes fear disappointing their oncologist. Both nurses present in the validation group believed this was an accurate consensus of the opinions in the two initial focus groups.

There was also consensus among nurses that quality of life is often overlooked in the face of cancer treatment, and suggested that decision-making incorporate a greater balance between aggressive therapy and overall patient wellbeing. The proposed early integration care model was viewed favorably because it would address quality of life at diagnosis and throughout treatment. Social workers also perceived a relative lack of attention to quality of life throughout treatment and embraced the proposed care model. This perspective was not as predominant among physician participants.

**Patient Education:** All providers agreed that misconceptions about the purpose of PC abound and that patients and families need to be educated about this service. Individuals in each focus group suggested a variety of methods including discussion with patients, providing lay literature, and external media. Nurse practitioners and nurses emphasized the need for more effective medical education beginning early in medical school and continuing into residency that clearly addresses the role of PC.

**Evidence-based Medicine:** Non-physician participants noted the lack of evidence-based literature regarding trials of early integration of PC. In addition, they believed that conducting a pilot study, with a select population of patients and physicians, would best facilitate understanding this care model. The overall risks to patients in such a study were perceived to be low by this group. They also believed it would provide valuable data about this complex topic, while physicians did not express such an interest.

#### Discussion

This study demonstrates that diverse perspectives exist among pediatric oncology providers regarding early integration of PC for children diagnosed with cancer. Prior research indicates concerns about prognosis and family preparedness regarding a potentially incurable disease were the most common barriers to PC.<sup>5, 7</sup> However, other studies indicate these concerns are unfounded.<sup>14, 15</sup>

Access to a PPCT in pediatric oncology continues to be an issue as only 58% of Children's Oncology Group institutions having a PPCT and only 6% of these institutions discuss PC at diagnosis.<sup>16</sup> Although additional evidence indicates the availability and utilization of PC services have increased over the past decade, demand for greater involvement of palliative care for children diagnosed with cancer remains.<sup>1</sup>

Our study found perceptions about adequacy of PC differ between provider types where physicians tend not to perceive unmet needs, while nurse practitioners, social workers and nurses see a significant problem. Solutions identified included improving communication and documentation. Importantly, many of the facilitators identified could also address barriers, as suggested by the complex relationships between the barrier and facilitator themes.

Another important finding in this study is the tension among oncology providers regarding patients' needs, suggesting that care for this population can generate significant emotions about how to improve care, with resistance to changing current practice, especially if it alters the relationship oncologists have with patients and families. We found resistance among physicians to give up traditional roles to allow early integration of a PCCT. In addition, we found conflicting philosophies about whether PC is consistent with curative therapy, which served as a barrier to early PC, which differed from the non-physician groups. Although all providers had concerns about patient readiness to receive PC, the non-physician groups recognized oncologists' influence in conveying hope for cure in the face of a poor prognosis. This finding is important as efforts are increasing across the U.S. to provide team-based care, <sup>17, 18</sup> but if competing agendas exist within and between teams, care will likely be affected.

All providers expressed concern that meeting the PPCT early may increase anxiety in families, complicating an already stressed family dynamic. Thompson, et al. asked general pediatricians about their preferred timing of PC referrals for patients with cancer, and 44.2% believed end of life (EOL), when cure is no longer the goal, was the most appropriate time.<sup>6</sup> Most nurses and both social workers felt that basing the timing of referral on prognostic information alone would limit access to PC for patients who could benefit from this service. Non-physician groups believed that early integration of a PPCT would improve patient care by providing an unbiased perspective regarding physical, psychosocial and spiritual symptom management, and by improving interdisciplinary communication. There are benefits to patient care even if a PPCT is involved late<sup>20</sup>, and there may be early benefits as well. In addition, limiting PC to EOL can place additional burdens on families when code status, location of death, and symptom management can lead to parents feeling less prepared<sup>1</sup> and less familiar with the PPCT.

Our study participants agreed a family's aversion to PC is often related to misconceptions regarding PPCT's purpose and the services they provide. All providers endorsed educational opportunities to address misperceptions along with inclusion of educational materials family members review with nursing staff at diagnosis.

Loss of hope may result in avoidance of difficult conversations at critical moments in the course of cancer therapy. Knapp, et al. found that of 81.2% of pediatricians surveyed reported experiencing difficulty talking about EOL issues, and 77.6% reported not wanting parents to give up hope for their child.<sup>7</sup> Our study identified the possible influence of physicians' emotions on treatment decisions, which could potentially lead to unrealistic goals of therapy. This finding is consistent with previous studies that suggest treatment decisions for children during the EOL period are highly influenced by the physician,<sup>5, 6, 7</sup> with potentially negative consequences. For example, an uncertain prognosis may lead to suffering from attempts at life prolonging therapies, delayed preparation for the EOL period, and moral distress on the part of staff if they feel the child is suffering from those treatments. Nurse practitioners and social workers in our study emphasized how physicians' emotions influence how they convey information to parents. The addition of an objective opinion beginning at diagnosis and continuing throughout treatment could improve care for children diagnosed with cancer, particularly at times of relapse or progression.

Our study addressed pediatric oncology providers' perceptions of barriers and facilitators to early integration of a PPCT in pediatric oncology. Our study was novel because few studies on the use of PC have used qualitative methods.<sup>3</sup> Prior studies utilized a survey design method,<sup>2,5–8,14–16</sup> and are limited by the inability to capture in-depth information, which can be obtained in the dynamic dialogue that often occurs with focus group methodologies. Furthermore, few studies have investigated barriers or facilitators to a novel proposal, in this case, early integration of a PPCT. By conducting validation focus groups, coupled with iterative analyses using NVivo, we further substantiated our findings. Qualitative methodology focuses on thematic identification, which will inform the next step of our research, survey formation. These will be designed to capture numerical variables and relationships. We chose to use the proposal to standardize the stimulus that our focus group participants reacted to. This technique resulted in very thoughtful responses from participants. We intend to alter the proposed model for early integration of a PPCT based on our findings. Though a consensus was not achieved across all provider groups, a revised care model would continue to focus on addressing the parents understanding of diagnosis, prognosis, treatment options, pain and symptom management, support systems and education. In addition, we would change the follow-up time points from every three months, as described by Temel, et al.<sup>21</sup>, to within the first month of diagnosis with follow-up on an as needed basis. There was consensus that end of therapy follow-up with the palliative care team would be another important check point as families experience anxiety during this transition to fewer clinical appointments and no cancer-directed therapy.

Our study has several limitations. Although we captured multidisciplinary perceptions, our study is limited by being from a single institution. Selection bias may have influenced our findings, as those with strong opinions in favor of or against the topic of PC were likely to attend. A disproportionately low representation of nurses (29%) is another weakness. We attributed this to personal obligations and the inability to step away from patient. Though perspectives were fairly uniform in the initial nursing groups, we can't be certain we captured all perspectives in the validation groups. Identifying a time for all of the initial participants was not possible. Also, hierarchical persuasion may have been present in the attending/fellow group, which may have altered responses from the fellows. However, over half the fellows provided in depth perspectives that did not always reflect the sentiment of the attendings. We plan to conduct additional research based on the current study to overcome these limitations.

In conclusion, this study provides important insights on the perceptions of pediatric oncology providers about PC. We found very different perspectives from physician and non-physician participants, all of whom share the goal of providing excellent care, but differ on

how to best achieve this despite working on the same healthcare teams. Future research should address how the barriers and facilitators to early introduction of PC for children with cancer we have identified can be used to improve the care of these patients.

#### Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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#### Table I

#### Proposal for the Early Integration of a Palliative Care Team\*

Content Area	Proposal Specifics
Consult Population: Identifying patients eligible for inclusion.	<ul> <li>Patients with any <i>new diagnosis of cancer</i></li> <li>Patients who undergo a change in goals of treatment at any time throughout the course of disease,</li> <li>Patients with on-therapy progression or development of metastatic disease</li> <li>Patients undergoing a stem cell transplant (standard of care at study institution)</li> <li>Patients entering a Phase I clinical trials (standard of care at study institution).</li> </ul>
Consultation Timing: When first and subsequent follow-up consults would occur.	<ul> <li>First consult <i>within the first month</i> of diagnosis</li> <li>Subsequent <i>consults at 3-month intervals</i> and as determined by the primary oncologist, at the time of progression, relapse or change in goals of care for established patients.</li> </ul>
Consultation Content: Topics to will specifically be addressed during the consultation.	<ul> <li>Educate family about the definition of palliative care as described by the AAP<sup>3</sup>.</li> <li>Determine family members' understanding of their child's illness with respect to prognosis, treatment options, and goals of therapy</li> <li>Pain and symptom management</li> <li>Assess and provide psychosocial support to families caring for a child with a life threatening disease</li> </ul>
Consultation Documentation	• Content of each consult recorded in the health record.

\*Modeled after protocols developed by Temel et al. and Baker et al.  $^{21,22}$ 

#### Table II

Demographic and Clinical Practice Characteristics of Focus Group Participants (n = 31)

Participant Characteristics	Value
Mean Age in Years (Range)	40.8 (29–66)
Gender	
% Male (n)	32 (10)
% Female (n)	68 (21)
Clinical Role	
% Pediatric Oncologist (n)	32 (10)
% Pediatric Oncology Fellow (n)	16 (5)
% Pediatric Oncology Nurse Practitioner (n)	16 (5)
% Pediatric Oncology Social Worker (n)	6.5 (2)
% Pediatric Oncology Staff Nurses (n)	29 (9)
Mean Calendar Year Highest Level of Training Completed (Range)	2001 (1977–2010)
Mean Number Years Spent in Clinical Practice (Range)	10.8 (1-34)
Mean Number Years Spent in Clinical Practice at Study Institution (Range)	7.2 (1–20)

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# Table III

Dalberg et al.

# Barriers, Definitions and Exemplars

Barrier	Definition	Exemplar	
Provider Role	Overlap between the	•	"The definitions of what a palliative team's role are exactly what the primary oncologist is doing" – Physician
	pulliative care team exists	•	"I think this is going to make the oncologist look bad" – Physician
	which is related to maintaining control on behalf of the physician	•	"Do you need another group of people when you have an oncology team whose job it is to do a lot of these thingthere is a whole primary team whose goal it is to do that, I mean, that's your job" - Nurse Practitioner
		•	"I don't know if I'd trust the palliative care team to do as well as the way I would want it to be done" – Physician
		•	"For the physicians, it's a control thing" – Nurse
		•	"I don't know that the palliative care team has a lot more to offer to a patient during their therapy than the primary oncology team" – Physician
		•	"Overlapping discussions will decrease trust" – Physician
		•	"It would provide a system of checks and balances" – Nurse Practitioner
		•	"I would have a problem if the palliative care team talked about prognosisI think that should be part of the primary team" – Physician
Conflicting Philosophy:	Palliative care does not appear to be in sync with	•	"The palliative care team's idea of the patient's quality of life is to not do chemotherapy and to let them die of their life- threatening disease" – Physician
	curative intent	•	"A very small percentage of people even know what that word means" – Nurse
		•	"I don't agree with this (proposal) in the early phase where the intent is cure" – Physician
		•	"No matter how we redefine palliative care, the world has not redefined palliative care" – Social Worker
Patient Readiness:	The palliative care team	.	"I worry about the emotional burden that we are potentially putting on families" - Nurse Practitioner
	may provoke anxiety	•	"Its going to be a burden regardless" – Nurse
		•	"The burden that may be added during diagnosis is less than burden from meeting the team for the first time at relapse" – Social Worker
		•	"Are you going to cause more harm by bringing in a palliative care team for low-grade diseases?" – Physician
		•	"A lot of the time the provider says, well they're not ready to have a palliative care team come in, whereas the nurses might think differently because they may hear some of their dialogue and they hear a lot of the behind the scenes stuff that not a lot of providers hear" – Nurse Practitioner
Emotional Influence:	Physicians may have difficulty in objectivity	•	"I definitely treat my patients different than I necessarily treat other people's patients because I have a buy-in and investment" – Physician
	whith their own patients; physicians may equate a patient death with a failure	•	"I don't think it's that our physicians don't recognize when palliative care is appropriate. I think they don't recognize when palliative care is appropriate in their patient" – Nurse Practitioner
	on their part, as well a sense of diminishing hope in patients and families.	•	"Part of me that really wants to hold on and keep pressing the family to go for curative intent and it's maybe not the rational thing to do" – Physician

	"Physicians feel it's their job is to cure this disease, and when they can't cure it there is a failure" – Nurse Practitioner	"We try to put a positive spin on a bad situation, which is the responsible thing to do" – Physician	"I don't think some doctors tell them there's no hope for cure; they say there are some Phase I studies we might be able to enroll them on, and you just never know what will happen" – Nurse	
Exemplars	•	•	•	
Definition				
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Exemplars	
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Definitions	
Facilitators.	

Facilitator	Definition	Exemplar	
Patient Eligibility and Timing	A higher risk patient population would be more	•	"If you are doing it at 50 percent (survival), is there another 40 percent that could benefit from our extra care that would focus on their coping ability, knowing that we're focusing on pain and symptom management" – Nurse Practitioner
	suitable, the timing of which is unclear.	•	"There can be kids with a good prognosis and the family still isn't coping well" – Social Worker
		•	"Just with patients who are going to spend a lot of time in the hospital instead of doing most of their treatment outpatient" – Nurse
		•	"End of therapy is the time that stress goes up, we're done with treatment and there's a chance it will come back, so the end of therapy is a very good time point" – Physician
		•	"That would be part of the first assessment as how much do we do this again" – Nurse Practitioner
Overall Benefit	There is an added benefit to the overall care from early integration of a palliative care	•	"So if we say, yes we're going for a curative intent, the family is on board, they're excited, but is there something in the back of their mind that's saying. I do have this life threatening disease and I can't talk about because I in going for cure " – Physician
	team	•	"Why would we wait a month to say, you're pain and symptom management and issues of quality of life are important to you and how can we help you manage that through treatment " – Social Worker
		•	"It's helpful to have the palliative care team to ask what you really want to do and does that really align with family's goals" – Physician
		•	"When families do accept the Bridges (palliative care) consult, it seems like they get a lot of wonderful things out of it" – Nurse
		•	"If it's standard of care, it's very simple; it's the standard of care rather than meeting the death squad" – Physician
		•	"If everybody gets it, it is not singling out any one diagnosis" – Social Worker
		•	"I think if it were presented as standard of care, it would alleviate a lot of the anxiety" – Nurse
Education	Focus on educating families	.	"Hearing the definition of palliative care up front would be different than when you have a setback" – Nurse
	and providers	•	"Palliative care is often translated as end-of-life care" - Social Worker
		•	"I don't think a large part of our medical education is geared to address this" – Nurse Practitioner
		•	"The idea of having a pamphlet in the binder is a good idea" – Nurse Practitioner
Evidence Based Medicine	To more feasibly address early	.	"You can trial it with an attending who buys into it and is taking new patients" - Nurse Practitioner
	integration of a pediatric palliative care team	•	"(If a study is conducted) we have learned something" – Social Worker
Enhanced Communication	This would improve	•	"I work nights and am never involved in these kind of discussions, and there is a lot of frustration" – Nurse
	intercursuptinary documentation and communication as well as	•	"Fishing out specific information about a conversation that was had or when there's changes in treatment plans is still a challenge" – Nurse
	patients' understanding of disease-related information	•	"(documenting important conversations) is an area that we really fall short on" – Nurse

Facilitator	Definition	Exemplars
		• The have a very well defined note that says everything would be really nice " – Nurse
		<ul> <li>"As somebody who works with a bunch of different physicians, different physicians are better or worse at gathering this information." – Nurse Practitioner</li> </ul>

Dalberg et al.