Codesigning an Intervention for Pediatric Oncology Teams: The Confronting Adversity through Regoaling Engagement (CARE) Project

Children with advanced cancer are often not referred to palliative or hospice care before they die[1] or are only referred close to the time of death.[2] Palliative care referrals may be delayed because clinicians are unfamiliar with palliative care, unsure of when referrals are appropriate, uncomfortable with the uncertainty inherent in children with serious illness[3], worried about upsetting families by mentioning palliative care[4,5], experiencing negative emotions when considering palliative care, or viewing palliative care referrals as professional failures.[6,7]

Pediatric cancer clinicians, importantly, do not work alone, but instead in interdisciplinary oncology teams that include physicians (MDs), nurse practitioners (NPs), social workers (SWs), nurses, psychologists, and trainees.[8] Team level barriers to initiating palliative care may include diverging opinions among team members, group norms in favor of curative treatments, lack of guidelines for initiating palliative care, ambiguity about which team members should begin the discussion, and hierarchical barriers.[9,10] While communication training helps individual clinicians discuss difficult topics with patients and family members[11,12], most existing interventions do not address potential team-level barriers.

This document provides outlines and materials used in a Codesign process to modify and tailor an intervention for three pediatric oncology teams (Neuro-Oncology, Solid Tumor, and Bone Marrow Transplant(BMT)) at the Children's Hospital of Philadelphia (CHOP).[13] This project was conducted within the context of our team's work designing the Confronting Adversity through Regoaling Engagement (CARE) Discussions and Conversations intervention.

The outlines of the codesign sessions, handouts, and activity descriptions are provided below so that other institutions can use them as a model to develop interventions tailored to teams in their own institution. The materials are intended to serve as resources for codesigning palliative care referral interventions that are appropriate for a particular institution, rather than as an off-the-shelf intervention that can be implemented at any institution. Pediatric palliative care providers at other institutions are encouraged to use the posted materials as a starting point for conducting their own codesign sessions with clinicians at their institution to develop an intervention meeting the needs of clinical teams interested in improving their palliative care referral process.

Overall CARE Project

The CARE project consists of four stages:

Stage 1: We observed clinical team meetings and conducted interviews with individual interprofessional team members to characterize team discussions about patients appropriate for initiation of palliative care in several oncology subspecialties (BMT, solid tumor and neuro-oncology) and to assess interprofessional team member perceptions of initiation of palliative care and subspeciality palliative care consultations.[13]

Stage 2: (The focus of this document) We partnered with interprofessional team members to codesign team-specific interventions for three pediatric oncology teams at CHOP.[14]

Stage 3: (manuscript in preparation) We assessed the feasibility of implementing the team-based interventions developed in the codesign process to: a) increase understanding of the scope of palliative care and variation in perceived timing appropriate for initiation of subspeciality consultation, b) how to manage clinical uncertainty regarding prognosis, c) best techniques for team communication and collaboration in challenging cases in which it is not clear which care options to offer patients and families, and d)best practices in discussing subspecialty palliative care consultation with families.

Stage 4: (manuscript in preparation) We conducted post-intervention interviews with codesign and intervention participants to assess interprofessional team member perceptions of initiation of palliative care and subspeciality palliative care consultations.

Overview of CARE Codesign Sessions

Members of pediatric interprofessional oncology teams were invited to participate in several tasks:

a) the selection and expansion of several hypothetical patient cases that may elicit a variety of perceptions of whether it is appropriate to initiate palliative care and brainstorming about potential challenges to initiation of primary palliative care or referral to pediatric palliative care specialists (PPCS).

b) selection among techniques for management of uncertainty of prognosis and brief mindfulness activities that can be used for managing clinician emotions.

c) selection among team training elements that will optimize communication and team collaboration in determining which options to offer patients and families.

d) refining hypothetical cases that will become basis for team discussion about initiation of palliative care with intention of requiring use of team best practices in communication.

Experience Based Codesign (EBCD) is method for obtaining information about the experiences of patients, family members, and staff to improve the experience of patients and family members.[15] The codesign approach draws on design approaches from other fields such as architecture, computer, product and graphic design. EBCD has been applied in oncology [16-18], neonatal intensive care (NICU)[19,20], and mental health settings.[21]

Interprofessional team co-designers were recruited from each of the three oncology teams participating in the study including physicians, nurse practitioners, and social workers. We offered 4 different codesign sessions with two times available for each one (a total of eight codesign sessions). Each session included participants from multiple teams and disciplines. Please see Hill et al. 2018 for additional detail about the procedure.[14]

Note that we conducted the codesign sessions to modify and refine the materials we later used in a 4-session intervention with each specialty team. Therefore, the materials below include descriptions of 4 **codesign** sessions (what we did in this stage of the project, see page 4-5) and descriptions of 4 **intervention** sessions (what the codesigners gave feedback on and was implemented in a later stage of the project, see page 6-11).

Codesign Session 1 Outline: Selection and revision of hypothetical cases for discussion

The overall goal of this codesign session was to a) familiarize the participants with the co-design process and the overall curriculum goals for the final intervention and b) to review a set of potential hypothetical patient cases (see page 12-19) that were designed to elicit a variety of responses of whether it is appropriate to initiate palliative care. The cases were intended to trigger brainstorming about potential challenges to initiation of primary palliative care or referral to pediatric palliative care specialists (PPCS).

Outline for Co-design Session 1

I. Brief overview of 4-day intervention and codesign process
II. Review of potential hypothetical patient cases for intervention session 1
    a. Case Goal: patient prognosis is clearly poor, the team would agree that the patient is appropriate for palliative care referral, but the team does not yet know what the family wants.
III. Review of potential hypothetical patient cases for intervention session 2
    a. Case Goal: there is uncertainty about patient prognosis or significant patient suffering and individual team members might be uncertain about whether palliative care is appropriate or not.
IV. Review of potential hypothetical patient cases for intervention session 3
    a. Case Goal: the team or family might question whether treatment plan is the right path and it may be challenging for the team to determine which care options to offer the patient and family.

Participants were asked the following questions about each case:

- Are the medical facts of the case clear?
- Would it be helpful to have a summary of the patient's medical condition for team members who are less familiar with the disease/terminology?
- Does the case meet the goals of the session? If not, how would you change the case?
- (If necessary) If you were to write a case for your subfield, what would it look like for this topic to achieve this sessions' goals?

The original cases are shown on pages 12-19. The revised patient cases based on the Codesign process can be seen on pages 20-25.

Codesign Session 2: Selection of techniques to manage uncertainty of patient prognosis

We based the content of codesign session 2 on findings that health care professionals have trouble coping with uncertainty[22,23] and that low tolerance for uncertainty is associated with burnout.[24] Clinicians deciding whether to initiate pediatric palliative care often face uncertainty because children with life threatening illness have extremely variable prognoses and life expectancy.[25,26] Clinicians report that telling parents that their child might die (which many parents infer when palliative care is mentioned) is extremely stressful[3,27]. As a result, clinicians may be reluctant to mention palliative care until they are certain that the child is actively dying.

The session leader asked participants about negative emotions experienced when considering palliative care. The session leader introduced techniques for managing uncertainty and negative emotions based on mindfulness [28-30] and cognitive behavioral interventions.[31-33]

The codesign participants participated in activities of mindfulness, individual cognitive restructuring (thinking of cognitive errors they might personally make when considering palliative care), and group cognitive restructuring (saying aloud examples of cognitive errors team members might make and discussing possible challenges to these errors). The overall goal of this codesign session was to have participants choose which of these three potential activities would be most appropriate for their teams and for them to offer suggestions on how to revise/modify the activities if necessary.

I. Overview of intervention session goals
II. Mindfulness activity and discussion (See page 26-27)
III. Cognitive Insight Activity (See page 28-29)

Codesign Session 3: Select team role confusion activities and collaboration materials

We based codesign session 3 on reports from interdisciplinary palliative care teams that roles are often blurred and effective communication and collaboration between team members is challenging.[34,35] In other contexts, medical teams often report system level or structural barriers that hamper efforts to meet patient needs.[20]

The codesigners participated in activities to address knowledge gaps about roles and to appreciate of the roles of others. The codesigners discussed potential system level batteris to utilizing all team members and then reviewed potential materials related to collaboration including capacities for interprofessional team work, responsibilities for team members, and intra-team skills for discussions. The overall goal of this codesign session was to select among potential role confusion activities and materials designed to optimize team communication in challenging situations.

I. Overview of intervention session goals
II. Role Confusion Activities (See page 30-31)
III. Group Collaboration Skills Materials Activity (See page 32-34)

Codesign Session 4: Selection and revision of cases for sessions 3 and 4 of intervention

The overall goal of this codesign session was to refine hypothetical cases that would become the basis for a team activity about discussing initiation of palliative care with intention of using team best practices in communication.

I. Overview of intervention session goals
II. Case for Session 3 group collaboration activity (See page 35-37)
III. Case for Session 4 information asymmetry/megacode activity (See page 38-41)

Preliminary Outlines for Intervention Sessions

Note these are outlines for proposed intervention sessions that were described to the codesign participants. Codesign participants participated in some, but not all of the activities described below, and the outlines for each session were modified before we implemented the actual intervention which is reported elsewhere.

DAY 1: Poor patient prognosis but uncertainty of family reactions (1 hr)

I. Palliative Care Scenario Discussion 1 (20 min)
Discussion of advancing disease and whether appropriate to initiate subspecialty PC.
   a. 1 case with very bad prognosis but no information on parental preferences
   b. What is difficult about having this discussion with families?
   c. What criteria do you use to decide whether to initiate Palliative Care?
   d. Group leader will emphasize variation in criteria, and how team members often don't realize how much variation

II. Discuss perception of what is Palliative Care? (5 min)
   a. Overview of what might be primary palliative vs. what happens when patient referred for palliative care subspecialists
   b. Does not mean end of curative care: concurrent or complementary model
   c. It's an addition, not a transition

III. Elicit challenges to referral to palliative care (5 min)
   a. Uncertainty of medical prognosis (we will bracket until session 2)
   b. Worries about competence: asking for help from outside clinicians
   c. Personal attachment to patient and family/sense of responsibility
   d. Worry about being excluded or replaced by new clinicians

IV. Validation of challenges with review of the literature: Reluctance to ask for help/Desire to be independent/competence (10+ min)
   a. Studies showing trainees often reluctant to ask for help even when unsure
   b. Medical culture/training places emphasis on being competent/knowledgeable/independent. Worry that referring to PC seen as admitting failure—not that at all, but providing most comprehensive and excellent care. It's an addition, not a transition.
   c. Reframe as referral to PC is one more tool that competent clinicians use. Oncologists have time constraints so offering another resource to ensure

V. Personal attachment to patient and family/sense of responsibility (10 min)
   a. Evidence on link between good physician patient-alliance, empathy and patient outcomes: A clinician's emotional relationship and empathy with a patient can be an important predictor of patient satisfaction, especially among sicker patients[36] and hospice patients[37]. A good working alliance between clinicians and patients can also predict higher patient adherence to treatment[38,39]. Trust is particularly important in the relationship between oncologists and their patients[40]. The relationship between a clinician and the patient meets important needs for both, and in some cases physicians

report hurt feelings when a patient ends a relationship[41]. Psychological counselors often experience emotional difficulty when planning to end their treatment with patient[42].

b. A good clinician cares and empathizes with patient and family. But this strength can also make it difficult for some clinicians to refer to PC, seen as abandonment, handing family off to outsiders who don't know the family and patient as well as the clinicians who have already worked with them for some time[43]. Ideally, the patient's oncologist, primary care provider, and other specialists will remain fully engaged in the patient's care even after a palliative care team is involved[44].
c. Research on transitions from pediatric/adolescent care to adult care: pediatricians report that sometimes reluctant to refer older patients with complex medical issues to adult providers/clinics because clinicians are emotionally attached to patient and family (and vice versa)[45,46]. Psychological counselors report that it is difficult when a therapeutic relationship with a child ends (by choice or not) and they often worry about will happen to their patients[47,48].
d. Pediatric oncology nurses report feelings of conflict when know patient is dying: need to emotionally separate but don't want to abandon patient[49].
e. Clinicians can still be involved in care and support even after palliative care referral[43].

VI. Describe benefits of clear communication with families/patients from literature (5 min)
a. Impact of honesty on hope
    i. Many patients and family members report appreciating honesty from doctors, finding it more upsetting when they suspect that the doctor is hiding something from them [50].
    ii. Parents of children with cancer want know important information even if the information is upsetting, because it helps them make them make the best possible decision about their child's care. [51]. The parents in this study reported that the uncertainty of feeling poorly informed about what was happening was more distressing than the bade news. In addition, learning bad news about their child's cancer prognosis did not make parents lose hope[52]. See Mack and Joffe 2014 and Mack & Smith for good review of these issues in adult and pediatric populations[53,54].
    iii. Parents of dying children report continuing to hope for a miraculous recovery while being quite aware of the severity of the child's illness and making practical preparations for the undesired outcome and preparing for loss [52,55].

b. Parental request for timely information
c. One study found that physicians reported knowing that a child was dying up to three months before the parents did this suggesting that critical information was either not being shared, was not being understood, or both[56].

DAY 2: Uncertainty regarding patient prognosis (1 hr)

I. Palliative Care Scenario 2 (introduce cases with high level of uncertainty in prognosis)—1 case of progressing disease but still some treatment options, 1 case of decent prognosis but lots of suffering (15 min)

a. Would you refer this patient for palliative care or wait until the prognosis is more clear?
b. 3 min writing exercise: How do you tend to manage uncertainty? How do people from your discipline tend to manage uncertainty more generally?
c. How long is appropriate to wait if the prognosis is unclear?
d. Do different team members respond differently to family responses (e.g. if family resists PC is that seen as end of discussion or just normal starting point?)
e. Is there a way to respond to suffering that isn't perceived as "throwing in the towel" or "sending the wrong message"? How can to the team absorb the suffering?

II. Discussion of how to manage uncertainty in prognosis drawing on literature (10 min)

a. Uncertainty about prognosis is often mentioned as a barrier to initiating palliative care.[57]
b. Discomfort with uncertainty can be source of anxiety, stress, and burnout for many clinicians, especially when the clinicians are worried about bad outcomes for patients [24,58]. Individuals in other settings sometimes postpone decisions or continue seek information that is not available because of negative emotions involved in the decision or anticipated negative emotions (e.g. anticipated regret if the individual makes the wrong decision)[59,60].
c. Family members of seriously ill patients report that while learning about uncertainty is difficult, it is also helpful[23].
d. Postponing letting parents know that a child's condition is uncertain can deprive parents of the ability to prepare for the child's death if the child dies suddenly.[61]
e. Can be helpful to accept uncertainty and learn how to communicate about it with patients and families.
f. One team of researchers on communicating about bad news to patients and families recommends handling uncertainty[22]:
    a. Normalize the uncertainty of prognosis: "I understand that you want more accurate information about the future. The reality is that it's like predicting the weather — we can never be absolutely certain about the future. I wish I could be more certain."
    b. Address patient and parent emotions about uncertainty, acknowledging how difficult it must be for them not to know, and offer counseling or refer to appropriate support for emotional and psychological strain.
    c. Avoid getting stuck in limbo, of waiting indefinitely for more information or certainty that may never come (e.g. postponing palliative care until clear that patient is actively dying). Patients may miss important opportunities to spend time with family, make most of remaining time, prepare for death because too focused on future. Help patient/family refocus on here and now "What can we do to help you now, given that we are unsure of exactly what the future will bring?"
    d. Recognize your own reactions to uncertainty and how it influences interactions with patients and families (being too optimistic, ordering endless tests, avoiding all discussion of the future.)
    e. Idea of having an "escape hatch" when you hit a communication wall. May feel pressure to offer treatment because what else can you do when you hit the

wall? But offering an empathetic statement or taking a break (with a commitment to come back and continue discussion) gives clinician an alternative to default of offering a treatment.

g. PACT team expert at managing uncertainty—they hear, listen, and support staff, patients, and families[62].

III. Discussion of signs in oneself and colleagues (e.g., anxiety, uncertainty) that may influence decisions about treatment goals. (15 min)

a. INTERVENTION: Demonstration of evidence based strategies for managing negative emotions. [*Each team can choose to do a mindfulness based mediation based on MBSR research or cognitive insight activity based on cognitive behavioral therapy research.]*

b. Mindfulness based stress reduction (MBSR) is a form of non-religious awareness meditation based on the idea of intentionally regulating the attention from moment to moment to achieve a state of detached observation of body sensation, thoughts, and emotions.[28]

i. MBSR interventions have been shown to help patients cope with chronic pain, discomfort, cancer treatment, heart disease, anxiety, and depression.[29,63,64]

ii. Some studies have shown that mindfulness meditation can increase cognitive flexibility, working memory, ability to regulate negative emotions such as anxiety, and ability to focus on tasks while under stress.[65-68]

iii. MBSR interventions have also been found to help clinicians cope with stress, increase well-being, increase empathy for patients, and reduce burnout.[30,69,70]

c. Mindfulness Mediation Activity

i. 5-10 minute meditation in which participants will focus on breathing, bodily sensations, thoughts, and emotions while thinking about a difficult patient care decision.

ii. Goal of activity is to identify physical, mental, and emotional signs of stress and uncertainty, and learn a method of refocusing the attentions to make these experiences more manageable.

d. Cognitive Insight Activity

i. Based on Beck's Cognitive Behavioral Therapy[31,71], this activity focuses on identifying recurring negative thoughts and generating counter arguments to these thoughts.

ii. Participants will be asked to identify negative thoughts they might experience while considering the possibility of palliative care (e.g. "I'm a failure because my patient is dying." "I should be able to find a cure for my patients.") and attempt to challenge these beliefs in a way shown to help reduce negative emotions associated with stressful situations.[32,33,72]

Day 3: Uncertainty about the Team's Response: Group Collaboration and Role Confusion (60 min)

I. Palliative Care Scenario 3 (15 min, see page 17-19)—Case 1 parent questions whether on the right path given goals and child's suffering. Case 2 would be team members raising this question when they think family is treating too aggressively.

a. Would you or other team members be unsure about whether PC appropriate? How might this influence the decision to initiate palliative care?
b. How would you express your concerns to other team members?
c. Would this have any impact? Why or why not?
d. How might PC help you initiate discussions about whether still on the right path. How do you adjudicate what the right path is? Is this left up primarily to the family?

II. Do you know what your colleagues offer?/Appreciating Others' Contributions/ Role Underutilization due to systems level factors (15 min)

1)Literature Review

a) even teams with strong tradition of and interdisciplinary approach report being unsure about what team members in other disciplines do.[34]
b) Flexibility in roles can be a strength of interdisciplinary teams but can also lead to conflict if boundaries between different professional roles is unclear.[35]
c) Team based interventions to increase awareness of how other team members care for seriously ill patients are associated with improved team dynamics and lower stress.[73]

2) 3 potential reasons why underutilized: lack of knowledge of skills, undervaluing skills, system challenges to utilizing skills [*Each team can choose from the role and communication activities below.]*

a) Role exercise about how to share what you do with others

b) Role exercise to reflect on an experience where you appreciated the expertise and skills of a colleague from another discipline.

c) Role exercise to describe an experience where you encountered a system level barrier to interprofessional collaboration.

III. Team Communication (Skills and attitudes modified from UCSF Team Talk Materials: 3 options) (15 min) (See page 26-27)

a) Capacities for Challenging Conversations and Interprofessional Teamwork
   i) Self awareness
   ii) Compassion
   iii) Response flexibility
   iv) Reflective practice
b) Responsibilities of all team members
   i) Contribute your expertise
   ii) Generosity and Respect
   iii) Discipline and Patience
   iv) Curiosity
   v) Trust
c) Intra-Team Communication skills
   i) Invite participation
   ii) Friendly questions
   iii) Seek permission

iv) Kudos
v) Yes, and…
vi) Support to disagree
vii) (re)Focus on the patient

IV. Group Collaboration Activity with facilitation highlighting skills from IV. (See page 28-29) (15 min)

i) team asked to care for patient with new mass that is new to family that came with belief team could help them.

ii) give people different roles so they aren't theirs and tell them is will be like a debate with different stances but how will they figure out to work together given these different believes/perspectives.

Day 4: Handling asymmetric information within the team: Megacode (60 min)

I. Review team skills/responsibilities that were covered in Session 3
II. Simulated group discussion of a patient where it is challenging for the team to determine whether to engage subspecialty palliative care and what to discuss with the family. Different information and perspectives will be assigned to different team members to simulate real-life case. (50 min, see page 38-41)

a. Discussion of role for team discussions of discussion leader to:
    i. facilitate group discussion
    ii. ensure team members from each discipline are acknowledged and encouraged to offer input
    iii. exchange of new information and suggestions
    iv. discussion of pros and cons of treatment including palliative care option
b. Designation of someone to initiate difficult discussion with family
c. Support persons to initiator of conversation

III. Wrap up: Discuss how you can apply techniques in unit (10 min)

Initial Case Discussions Reviewed in Codesign Session 1

We prepared three patient cases to trigger discussion on specific topics in the CARE intervention sessions based on the following criteria: 1) patient prognosis is poor with no curative options left, but the team does not know what the family wants; 2) patient prognosis is uncertain or patient has significant suffering but treatment options still exist, so team members might disagree about whether palliative care is appropriate; or 3) the team or family might question the chosen treatment plan, and there is likely conflict about whether to involve palliative care. We initially planned to use the same general cases to trigger the discussions for each subspecialty (e.g. use a neuro-oncology case for all three teams in Intervention Session 1).

Below are the ten initial cases we asked the codesign participants to give feedback on.

Potential Session 1 Cases:
Cases with poor patient prognosis and uncertainty about what family would want.

Case 1: 9yo with Burkitt's lymphoma

9yo male with Burkitt Lymphoma. He was diagnosed 6 months ago and initially received cytoxan, vincristine, and prednisone (standard "pre-chemo" given initially secondary to the tremendous risk for rapid tumor lysis with full dose chemotherapy). This course was complicated by a prolonged ICU stay with life threatening complications including renal failure requiring dialysis, typhlitis requiring an exploratory laparotomy resulting in an ileostomy, bacterial and fungal infections, and ventilator dependent respiratory failure.

His subsequent cycle of chemotherapy was appropriately delayed while awaiting recovery from these complications. He received only part of his next cycle of chemotherapy with subsequent prolonged neutropenia.

Restaging at count recovery showed improved disease and possibly a remission. However, because of prolonged neutropenia, he was not able to receive more chemotherapy until 8 weeks later. At that time, scans showed dramatic worsening of disease in the chest and abdomen. Four months ago, he received intense chemotherapy with different chemotherapeutic agents, which he tolerated this time without difficulty.

Follow up scans showed persistent albeit improved burden of disease. He received another cycle of "light" chemotherapy that resulted in another episode of unusually prolonged neutropenia. At this point, not only does he have chemo-refractory disease, he also appears to have some constitutional problem tolerating chemotherapy. The team strongly suspects a DNA repair defect, which would mean severe side effects to most chemotherapy that could be life threatening because of the inability for even the normal cells to repair themselves post chemo.

On a recent exam, there are newly palpable subcutaneous and chest wall lesions. The patient is increasingly tachycardic and tachypneic and appears to be in pain. He is admitted for pain and unstable vitals and you are meeting as a team to discuss what needs to be discussed with him and his family on this admission.

Case 2: 17 yo with Ewings

17yo year old male who presented with increasing pain and discomfort with limited mobility of his left arm and shoulder. Over the last several weeks he has also developed night sweats and increasing fatigue and malaise. He has had no respiratory symptoms, no fevers. No focal neurologic symptoms, but does feel generally weak and feels dizzy when walking long distances. He has significant pain that didn't improve with occasional oxycodone and tylenol (taking about once a day), and over the last few weeks has also developed diffuse bony pain and occasional neck and back pain. Physical exam revealed a large mass over his left scapula. Subsequent biopsy of the mass revealed a new diagnosis of diffusely metastatic Ewing sarcoma.

The team agrees that he has a poor prognosis and high likelihood that he will never be cured of his disease even with chemotherapy, surgery, and radiation. You are meeting as a team to decide what should be discussed with him and his family.

Case 3: 5 yo with DIPG

Five year old male who presented to outside hospital four months ago for repeated falls after a 2 month history of clumsy walking. A CT demonstrated enlargement of the brainstem. He was transferred to CHOP ED and then to the ICU. An MRI at CHOP revealed large pons-centered mass that appears very consistent with a diffuse intrinsic pontine glioma (DIPG). After meeting with the oncologist and hearing the prognosis that this tumor is universally fatal, the family asked for second opinions at a few other hospitals which the team facilitated for them with peer institutions. At discharge from the hospital one week ago, he was taking Dexamethasone 4mg BID. He comes in now with new symptoms of having a head tilt. He has been continuing to have some gait difficulties with balance but wants to be very active and independent.

The family is moving into a downstairs unit so that there are no stairs for him to have to climb. They feel he gets "jelly legs" around the time he is due for the next dose of steroids. The team increased his Dex from 4mg twice daily to 4mg three times daily to help with the increasing symptoms. You are asked to review with the family what they understand and what they've heard from the second opinions. You are meeting as a team first to discuss what you should talk about with the family.

Potential Session 2 Cases:
Cases with uncertainty about patient prognosis or significant patient suffering.

Case 1: 6yo with B cell lymphoma

6 year old female with failure to thrive, developmental delay, ataxia telangiectasia (AT), and chronic hepatitis presents with hepatomegaly and fever.

After an extensive work up and extended PICU stay, she is newly diagnosed with lymphoma in the setting of her underlying ataxia telangiectasia. Her pathology is consistent with diffuse large B cell lymphoma and she has disease in her lungs, liver, and abdomen without bone marrow involvement.

Active issues that remain are persistent ascites and high fevers despite broad anti-microbials, which create tenuous vitals at times and require frequent rapid response team calls.

Her mother is aware that treatment of malignancy in child with AT can be extremely toxic, and therapy can be fatal. She also understands that if the lymphoma is not treated, it will progress and be fatal. The team discussed with the family that the most common chemotherapies (e.g., alkylators, anthracyclines, etoposide, and vinca alkaloids) all need to be adjusted for patients with AT. There is significant uncertainty about the prognosis and ability to treat this cancer without full dose treatment. You are meeting as a team to discuss what to recommend to the family at this point.

Case 2: 9yo with B-cell ALL

9yo year old male with B-cell ALL. He has recently started maintenance therapy (the last part of treatment for leukemia which lasts 3 years and is normally predominantly given as an outpatient). However, he has been admitted for the last 10 months due to complications.

This prolonged hospitalization was precipitated by an episode of E coli sepsis and ARDS requiring a prolonged PICU stay. Upon recovery, after receiving PEG-asparaginase, he developed necrotizing pancreatitis that was complicated by a pancreatic duct leak that required several surgical interventions. Although this is generally improved and he no longer receives asparaginase, he suffers from frequent pancreatitis flares. In between episodes he remains NPO on TPN. He developed diabetes mellitus and is insulin dependent as a result of these frequent episodes of pancreatitis. He requires frequent glucose checks throughout the day and night secondary to episodes of hyper and life-threatening hypoglycemia.

During one particularly severe episode of pancreatitis three months ago, he developed E. coli sepsis a second time that resulted in multifocal septic arthritis/osteomyelitis in his bilateral lower extremities, particularly at the sites of previous avascular necrosis, another complication of chronic steroid use during his leukemia therapy. He has required four lower limb washouts and drains placed as well as several months of intravenous antibiotics.

He has excruciatingly painful neuropathies in his feet secondary to vincristine use and can no longer bear weight or move his feet. He can't get to inpatient rehab yet because he requires continuous TPN and a dilaudid PCA for abdominal pain from the pancreatitis.

Recently, an attempt was made to cycle his TPN. This resulted in DS of 30 for which a D10 bolus was given. He was weaning on his dilaudid PCA and was taking oral dilaudid throughout the day, however his pancreatitis flared and he was made NPO again.

He is currently unable to take most of his maintenance drugs secondary to these grade 4 adverse effects. He continues only on single agent methotrexate, however this is not given at full dose in order to maintain his ANC in a normal range to decrease risk of future life threatening infections.

He is unable to leave his room because he is almost always on precautions. He is depressed and anxious. He rarely has visitors because his parents have to work and his sister is in school. His cousin was visiting recently but was sick and he was unable to visit.

His family is happy that his leukemia is in remission, however they are struggling with the degree of suffering that he has had to endure. They want to stop treatment and take him home. He has expressed sadness, loneliness, and pain to them. They don't want him to go through another three years of this. You are meeting as a team to discuss what you will recommend for him moving forward when you have a family meeting later this week.

Case 3: 3yo with AML s/p BMT

3yo M who was diagnosed with AML after presenting with a several week history of fever, rash, and limp. He was treated per the standard risk AML therapy with suboptimal response which meant his best chance for cure was a bone marrow transplant. He underwent an unrelated donor cord blood transplant. SCT complications included pleural effusions requiring chest tube placement and hemolytic anemia secondary to cyclosporine. At approximately day 60, he was noted to have persistent emesis and decreased PO intake and found to have eosinophilic esophagitis. He was treated with budesonide with marked symptomatic improvement. Day 100 SCT evaluation demonstrated bone marrow remission. Unfortunately he experienced a bone marrow relapse 8 months later.

The only curative option at this point for this very high risk leukemia is another bone marrow transplant. There would be a need for a graft-vs.-leukemia/GVHD effect using unrelated donor peripheral stem cells. With a second transplant, the risk of chronic GVHD is worth taking for possible graft vs leukemia effect. The risks include mucositis requiring pain medication, poor appetite requiring IV nutrition, infection which can be life-threatening, acute and chronic graft-vs.-host disease, organ toxicity which can be life-threatening, and late effects including poor growth and sterility. There is also a significant risk of relapse post transplant. You are meeting as a team to discuss which treatment options to offer at the meeting with his parents later this week.

Potential Session 3 Cases:
Cases where team or family are questioning whether treatment plan is the right path with likely team conflict.

Case 1: 9yo M with Burkitt's

9yo male with Burkitt Lymphoma. He lives in New Jersey and is here with his parents. His 8 yo sister and 2 year old twin brothers are staying with his maternal grandparents several hours away. He and his family came to CHOP to pursue further therapy.

He was diagnosed 6 months ago and initially received cytoxan, vincristine, and prednisone (standard "pre-chemo" given initially secondary to the tremendous risk for rapid tumor lysis with full dose chemotherapy) that was complicated by a prolonged ICU stay with renal failure requiring dialysis, typhlitis requiring an exploratory laparotomy resulting in an ileostomy, bacterial and fungal infections, and ventilator dependent respiratory failure.

His subsequent cycle of chemotherapy was appropriately delayed while awaiting recovery from these complications. He received only part of his next cycle of chemotherapy with subsequent prolonged neutropenia. Restaging at count recovery showed improved disease and possibly a remission. Because of prolonged neutropenia, he was not able to receive more chemotherapy until 8 weeks later. At that time, scans showed dramatic worsening of disease in the chest and abdomen. He received intense chemotherapy with different chemotherapeutic agents, which he tolerated this time without difficulty. At this time, the family opted to transfer care to you from another hospital.

Family has been consistent with communication to the team in expressing wishes for cure. Father's second cousin had leukemia and it took three years to cure it, but now he is well and father continues to believe the same will be the case for his son.

Follow up scans at your institution showed persistent albeit improved burden of disease. He received another cycle of "light" chemotherapy that resulted in another episode of unusually prolonged neutropenia. At this point, not only does he have chemo-refractory disease, he also appears to have some constitutional problem tolerating chemotherapy. The team strongly suspects a DNA repair defect, which would mean severe side effects to most chemotherapy that could be life threatening because of the inability for even the normal cells to repair themselves post chemo.

His family consistently speaks of curing him. The team has met with his father on three occasions to explain the refractory nature of his disease and the suspicion for an underlying genetic syndrome leading to intolerance of chemotherapy. The team has expressed that the likelihood of cure is very low.

On exam, there are newly palpable subcutaneous and chest wall lesions. The patient is increasingly tachycardic and tachypneic and appears to be in pain. The father is very nervous about using morphine and does not allow its use because of a fear that it will make his breathing slower.

You caught his mother alone on one occasion. She shared that she thought patient was getting better after a couple recent episodes where he was playing with PT on the mat and asked to go to the grocery store for home cooked food. She believed that the newly visible lump on his chest was because he dropped the ipad on himself and was reluctant to believe it was from the cancer progression.

The bedside nurses are expressing concern that continued offer of aggressive treatments would not be good for him because of his history of significant life threatening complications and are

not sure if they are doing right by the patient. They have started talking about the need to consult the PACT team. You have a family meeting scheduled with the family for tomorrow and are meeting as a team to discuss your concerns about how to proceed and what should be discussed with the family.

Case 2: 6 yo with B cell lymphoma (if not used on day 2)

6 year old female with failure to thrive, developmental delay, ataxia telangiectasia (AT), and chronic hepatitis presents with hepatomegaly and fever.

After an extensive work up and extended PICU stay, she is newly diagnosed with lymphoma in the setting of her underlying ataxia telangiectasia. Her pathology is consistent with diffuse large B cell lymphoma and she has disease in her lungs, liver, and abdomen without bone marrow involvement.

Active issues that remain are persistent ascites and high fevers despite broad anti-microbials, which create tenuous vitals at times and require frequent rapid response team calls.

Her mother is aware that treatment of malignancy in child with AT can be extremely toxic, and therapy can be fatal. She also understands that if the lymphoma is not treated, it will progress and be fatal. The team discussed with the family that the most common chemotherapies (e.g., alkylators, anthracyclines, etoposide, and vinca alkaloids) all need to be adjusted for patients with AT. There is significant uncertainty about the prognosis and ability to treat this cancer without full dose treatment.

Because of the highly uncertain prognosis, mom has been given the choice of how to proceed and doesn't know what is best for her daughter. She has always known that AT brought an increased risk of cancer and now that she finds herself in this position, is uncertain how much suffering she is willing to tolerate for the sake of an unlikely cure. You are meeting as a team to discuss what you should recommend to the mom given her requests for guidance from the team and worry that she isn't sure what the right path is for her daughter.

Case 3: 9yo with B-cell ALL (if not used for day 2)

9yo year old male with B-cell ALL. He has recently started maintenance therapy (the last part of treatment for leukemia which lasts 3 years and is normally predominantly given as an outpatient). However, he has been admitted for the last 10 months due to complications.

This prolonged hospitalization was precipitated by an episode of E coli sepsis and ARDS requiring a prolonged PICU stay. Upon recovery, after receiving PEG-asparaginase, he developed necrotizing pancreatitis that was complicated by a pancreatic duct leak that required several surgical interventions. Although this is generally improved and he no longer receives asparaginase, he suffers from frequent pancreatitis flares. In between episodes he remains NPO on TPN. He developed diabetes mellitus and is insulin dependent as a result of these frequent

episodes of pancreatitis. He requires frequent glucose checks throughout the day and night secondary to episodes of hyper and life-threatening hypoglycemia.

During one particularly severe episode of pancreatitis three months ago, he developed E. coli sepsis a second time that resulted in multifocal septic arthritis/osteomyelitis in his bilateral lower extremities, particularly at the sites of previous avascular necrosis, another complication of chronic steroid use during his leukemia therapy. He has required four lower limb washouts and drains placed as well as several months of intravenous antibiotics.

He has excruciatingly painful neuropathies in his feet secondary to vincristine use and can no longer bear weight or move his feet. He can't get to inpatient rehab yet because he requires continuous TPN and a dilaudid PCA for abdominal pain from the pancreatitis.

Recently, an attempt was made to cycle his TPN. This resulted in DS of 30 for which a D10 bolus was given. He was weaning on his dilaudid PCA and was taking oral dilaudid throughout the day, however his pancreatitis flared and he was made NPO again.

He is currently unable to take most of his maintenance drugs secondary to these grade 4 adverse effects. He continues only on single agent methotrexate, however this is not given at full dose in order to maintain his ANC in a normal range to decrease risk of future life threatening infections.

He is unable to leave his room because he is almost always on precautions. He is depressed and anxious. He rarely has visitors because his parents have to work and his sister is in school. His cousin was visiting recently but was sick and he was unable to visit.

His family is happy that his leukemia is in remission, however they are struggling with the degree of suffering that he has had to endure. They want to stop treatment and take him home. He has expressed sadness, loneliness, and pain to them. They don't want him to go through another three years of this. His GI doctors believe he can eventually recover from the pancreatitis and tolerate PO feeds, but they don't have a timeline for this. His oncologists are hopeful that by adjusting his medication dosing he will have fewer side effects. You are meeting as a team before a scheduled family meeting tomorrow to discuss what you should discuss with the family and any recommendations the team would make.

Case 4: 5yo M with DIPG

Five year old male who presented to outside hospital four months ago for repeated falls after a 2 month history of clumsy walking. A CT demonstrated enlargement of the brainstem. He was transferred to CHOP ED and then to the ICU. An MRI at CHOP revealed large pons-centered mass that appears very consistent with a diffuse intrinsic pontine glioma (DIPG). After meeting with the oncologist and hearing the prognosis that this tumor is universally fatal, the family asked for second opinions at a few other hospitals. At discharge from the hospital one week ago, he was taking Dexamethasone 4mg BID. He comes in now with new symptoms of having a head tilt. He has been continuing to have some gait difficulties with balance but wants to be very active and independent.

The family is moving into a downstairs unit so that there are no stairs for him to have to climb. They feel he gets "jelly legs" around the time he is due for the next dose of steroids. The team increased his Dex from 4mg twice daily to 4mg three times daily to help with the increasing symptoms. The family met with PT in clinic. Their therapist offered a wheelchair and bedside commode for him but the family said they were not emotionally ready to have that medical equipment at home. The family is to meet with Dr. Lustig this afternoon to discuss radiation therapy IMRT as his symptoms are progressing and they want to do everything possible to find a cure. Some members of the team believe PACT should be consulted and the team is meeting to discuss whether they should offer this option to the family at this point.

Case Discussions for Intervention Sessions Modified based on Codesign Feedback

Codesigners offered suggestions on how to revise the patient cases for each of their teams. They suggested using team specific cases because they were not always familiar with terminology, prognosis, or treatment options in the other areas. We therefore developed separate cases for each team for Sessions 1-3 of the intervention, which were edited based on in-person feedback and follow-up e-mails.

Although the Liquid Tumor team was not able to participate in the CARE intervention at our institution, we developed liquid tumor cases that could potentially be used at other institutions.

BMT Intervention Session 1 Case: ***poor patient prognosis and uncertainty about what family would want.***

12yo with relapse s/p BMT

The patient is a 12yo male with a history of T-ALL who is s/p matched sibling donor BMT (induction/consolidation failure). He was conditioned with thiotepa, cytoxan, and TBI. He presented to clinic for a routine appointment 11 months post transplant with pancytopenia and was found to have an isolated bone marrow relapse. He received reinduction therapy with NECTAR and unfortunately recovered with blasts.

An attempt at a second reinduction resulted in significant complications, including multi organ system failure and an aspergillus respiratory infection. Low dose chemotherapy is being given in the interim, while he recovers. He and his family are still hoping to attain another remission and proceed to second transplant. MRD post re-induction remains grossly positive. You are meeting as a team first to discuss what you should talk about with the family.

BMT Intervention Session 2 Case: ***uncertainty about patient prognosis or significant patient suffering.***

17 yo with relapse s/p BMT

17 year old female with Monosomy 7 MDS s/p MSD BMT. Conditioning included thiotepa, cytoxan, and TBI. She presented to clinic for a routine appointment six months post transplant with pancytopenia and was sadly, diagnosed with relapse of her primary leukemia. She completed one cycle of intensive AML induction therapy with ADE, resulting in good disease control, but this cycle was complicated by a disseminated pulmonary fungal infection with associated respiratory failure. Her lungs improved, but unfortunately despite two cycles of lighter chemotherapy while waiting for respiratory improvement, her AML disease burden progressed.

After extensive discussion, she received intensive therapy in hopes of achieving disease reduction prior to a potential second stem cell transplant. Unfortunately, after a second intensive AML therapy cycle, MRD from her BM aspirate showed residual leukemia of 8%. She is currently receiving hydroxyurea, with stable peripheral disease. Since starting the hydroxyurea,

her activity level has increased and she is going out with friends. You are meeting as a team to decide what should be discussed with her and her family.

<u>BMT Intervention Session 3 Case:</u> ***team or family are questioning whether treatment plan is the right path with likely team conflict.***

16yo with AML s/p BMT

16yo M who was diagnosed with AML after presenting with a several week history of fever, rash, and limp. He was treated per the standard risk AML therapy and unfortunately, had refractory disease, necessitating a bone marrow transplant. He was conditioned with a TBI containing regimen and transplanted four months ago. His course has been complicated by Grade 3 skin and gut GVHD for which he has had several hospitalizations in the interim. Day 100 SCT evaluation demonstrated bone marrow remission. Unfortunately, he experienced a bone marrow relapse 1 month later at Day +129.

Patient has expressed to you privately that he does not want to go through more hospitalizations and pain. He expressed that his course has been difficult and he has not been able to enjoy time at home with his family and friends. His parents are adamant that they can't give up and want everything done. You are meeting as a team to discuss which treatment options to offer at the meeting with his parents later this week.

<u>Neuro-Oncology Intervention Session 1 Case:</u> ***poor patient prognosis and uncertainty about what family would want.***

7 yo with DIPG

7 year old male who presented with a one month history of repeated falls and clumsy walking. MRI revealed a large pons-centered mass that appears very consistent with a diffuse intrinsic pontine glioma (DIPG). The emergent medical issues were dealt with on admission and the family learned that there are no available clinical trials or curative therapies. They were devastated at hearing the dismal prognosis associated with this diagnosis and asked for a second opinion at a peer institution.

At discharge from the hospital one week ago, he was taking dexamethasone. He comes in now with new symptoms. He has had a worsening gait and difficulties with balance. The team increased his dexamethasone and referred them to radiation oncology to help with the increasing symptoms. You are meeting as a team first to discuss what you should talk about with the family and whether to consult palliative care at this time.

<u>Neuro-Oncology Intervention Session 2 Case:</u> ***uncertainty about patient prognosis or significant patient suffering.***

Patient is a 3yo female who presented with generalized tonic clonic seizure at daycare. Imaging showed a large heterogeneous tumor in the left posterior hemisphere. The resection was

complicated by hemorrhage into the tumor and resulted in a subtotal resection. In discussion with neurosurgery, based on the location of the residual tumor, it is felt to be inoperable. Tumor pathology obtained is consistent with an atypical teratoid rhabdoid tumor (ATRT). Further staging revealed no other tumor sites.

The patient recovered from the resection and was discharged home. She is returning to clinic to discuss plan for treatment, which may include chemotherapy and/or focal radiation therapy. You are meeting as a team first to discuss what you should talk about with the family and any recommendations the team would make.

Neuro-Oncology Intervention Session 3 Case: ***Cases where team or family are questioning whether treatment plan is the right path with likely team conflict.***

3yo F with relapsed medulloblastoma

Patient initially presented at 16 mo with early morning emesis and ataxia. A CT scan revealed a large posterior fossa mass. Tumor pathology confirmed a medulloblastoma. He achieved a gross total resection by MRI, however he did have disseminated leptomeningeal dissemination in the spine. He received 3 induction courses of chemotherapy with good response followed by 3 consolidation cycles of high dose chemotherapy with stem cell rescue with a full response to therapy. High dose chemotherapy and stem cell rescue is the standard of care in children less than three years of age with medulloblastoma.

He is now 3 years old and is presenting to clinic with early morning emesis and frequent falls. MRI results were concerning for recurrent disease. Craniospinal radiation may be an option for further treatment. However, he would likely remain permanently infantile and if he survived the disease he would have severe neurocognitive impairment that would preclude normal life and independence. You are meeting as a team before a scheduled family meeting tomorrow to discuss what you should discuss with the family and any recommendations the team would make.

Solid Intervention Session 1 Case: ***poor patient prognosis and uncertainty about what family would want.***

15 yo with Ewing Sarcoma

15yo year old male who presented with increasing pain and discomfort with limited mobility of his right arm and shoulder. Over the last several weeks he has also developed night sweats and increasing fatigue and malaise. He has had no respiratory symptoms, no fevers. He has significant pain that didn't improve with occasional Tylenol and over the last few weeks has also developed diffuse bony pain and occasional neck and back pain. Physical exam revealed a large mass over his right scapula. Subsequent staging and biopsy of the mass revealed a new diagnosis of diffusely metastatic Ewing sarcoma.

The team agrees that he has a poor prognosis and high likelihood that he will never be cured of his disease even with chemotherapy, surgery, and radiation. You are meeting as a team to decide what should be discussed with him and his family.

Solid Intervention Session 2 Case: ***uncertainty about patient prognosis or significant patient suffering.***

5yo with germ cell tumor

The patient is a 5 year old female diagnosed with an abdominal germ cell tumor one year ago. She was initially treated with surgery and cisplatin, etoposide, and bleomycin. While she had a good response to therapy, she suffered from renal and pulmonary insufficiency such that she was not able to receive full dose therapy. During her therapy, spent a significant amount of time hospitalized because of nausea and vomiting, feeding intolerance, and prolonged neutropenia. She expressed missing her older siblings who were in school and couldn't visit very often. After completion of therapy, she went back to her spunky personality and has been enjoying her summer before starting kindergarten. Her father has expressed gratitude that this is over and has shared that they would never want to go through intense treatment again.

Unfortunately, routine surveillance is now showing a rise in her AFP and new pulmonary nodules with an associated pleural effusion. You are meeting as a team first to decide what should be discussed and what recommendations to make to the family at this time.

Solid Intervention Session 3 Case: ***team or family are questioning whether treatment plan is the right path with likely team conflict.***

4yo with high risk neuroblastoma

4yo previously healthy male who is presenting with diffuse bone pain. He was found to have a right adrenal tumor concerning for possible neuroblastoma. Laboratory analysis and tumor pathology confirmed this diagnosis and further evaluation demonstrated MYCN amplification and metastases to his bones and bone marrow. He received routine induction therapy for high-risk neuroblastoma with no response to treatment. Given his lack of response to induction therapy, he proceeded to receiving high dose MIBG therapy, which he tolerated without complications or prolonged neutropenia.

Follow up MIBG scan 6 weeks later is concerning for significant worsening of disease in his abdomen and bones. In clinic he is found to have thrombocytopenia and a low grade fever with associated congestion and cough. His liver enzymes are elevated and he is jaundiced on exam. In addition, he is having significant abdominal and bony pain and is requiring up-titration of opioids for relief.

The family is hoping for a cure and has expressed the desire to continue to do anything possible to attain this goal. You are seeing him in clinic and are meeting as a team first to decide what should be discussed and what recommendations to make to the family at this time.

<u>Liquid Tumor Session 1 Case:</u> ***poor patient prognosis and uncertainty about what family would want.***

3yo with Burkitt lymphoma

3yo male with Burkitt Lymphoma. His initial routine chemotherapy course was complicated by a prolonged ICU stay with life threatening complications including multiorgan system failure resulting in an ileostomy, TPN dependence and renal insufficiency.

His subsequent cycle of chemotherapy was delayed while awaiting recovery from these complications. He received only part of the next cycle of chemotherapy given the previous life threatening complications. However, even with lower doses, he required another ICU transfer with multisystem organ failure from which he is still recovering. Restaging subsequently showed dramatic worsening of disease.

On a recent exam, there are newly palpable lesions. The patient is increasingly tachycardic and tachypneic and appears to be in pain. The lymphoma is progressing rapidly and he is so chemo intolerant that it would likely be unsafe to give him more chemotherapy. His prognosis is dismal, likely days to weeks with how quickly this lymphoma grows. You are meeting as a team to discuss how to discuss this with his family.

<u>Liquid Tumor Session 2 Case:</u> ***uncertainty about patient prognosis or significant patient suffering.***

7yo with B-cell ALL

7yo year old male with B-cell ALL. He has recently started maintenance therapy (the last part of treatment for leukemia which lasts 3 years and is normally predominantly given as an outpatient). However, he has been admitted for the last 10 months due to complications.

This prolonged hospitalization was precipitated by an episode of sepsis and ARDS requiring a prolonged PICU stay in the setting of severe necrotizing pancreatitis. He has been TPN dependent for the last several months and has developed insulin dependent diabetes mellitus. Despite recovery from the initial episode of sepsis, he has required several other PICU stays for sepsis that result in multi-organ system dysfunction and inability to give full dose chemotherapy. This has resulted in deconditioning, pain requiring IV opioids, neuropathic pain, and inability to bear weight.

<u>Liquid Tumor Session 3 Case:</u> ***team or family are questioning whether treatment plan is the right path with likely team conflict.***

3yo M with Burkitt's

3yo male with Burkitt Lymphoma. He lives in New Jersey and is here with his parents. His 8 yo sister and 2 year old twin brothers are staying with his maternal grandparents several hours away. He and his family came to CHOP to pursue further therapy. His initial routine chemotherapy

course was complicated by a prolonged ICU stay with life threatening complications including multiorgan system failure resulting in an ileostomy, TPN dependence and renal insufficiency.

His subsequent cycle of chemotherapy was delayed while awaiting recovery from these complications. He received only part of the next cycle of chemotherapy given the previous life threatening complications. However, even with lower doses, he required another ICU transfer with multisystem organ failure from which he is still recovering. Restaging subsequently showed dramatic worsening of disease.

Family has been consistent with communication to the team in expressing wishes for cure. The father's cousin had leukemia and it took three years to cure it, but now he is well and father continues to believe the same will be the case for his son even though the team has expressed that the likelihood of cure is very low given the lack of response to chemotherapy that is considered standard of care.

On a recent exam, there are newly palpable lesions. The patient is increasingly tachycardic and tachypneic and appears to be in pain. The lymphoma is progressing rapidly and you suspect that his prognosis is days to weeks. The father is very nervous about using morphine and does not allow its use because of a fear that it will make his breathing slower.

You caught his mother alone on one occasion. She shared that she thought the patient was getting better because he had improved energy in the last couple of days.

The bedside nurses are expressing concern that continued offer of aggressive treatments would not be good for him because of his history of significant life threatening complications and are not sure if they are doing right by the patient. They have started talking about the need to consult the PACT team. You have a family meeting scheduled with the family for tomorrow and are meeting as a team to discuss your concerns about how to proceed and what should be discussed with the family.

Activities for Codesign Session 2: Techniques to Manage Uncertainty

In codesign session 2, the codesigners participated in activities of: 1) mindfulness, 2) individual cognitive restructuring (thinking of cognitive errors they might personally make when considering palliative care), and 3) group cognitive restructuring (saying aloud examples of cognitive errors team members might make and discussing possible challenges to these errors). The overall goal of this codesign session was to have participants choose which of these three potential activities would be most appropriate for their teams and for them to offer suggestions on how to revise/modify the activities if necessary.

Mindfulness Activity Script

Before we begin, I'm going to ask each of you to put your phone on silent or sleep for 5 minutes so you don't have to worry about it ringing or vibrating during this exercise. I will remind you to turn your phone back on at the end of the activity.

When you know you have to have a difficult conversation with a parent or patient, where do you feel it in your body? For example, do you feel tension in your jaw or neck? Do you feel it in your stomach? Or maybe you don't have any particular physical sensation that you are aware of.

Now let's try a mindfulness activity to see how we can work through this feeling.

Let's start with a mindfulness of the breath. Sit quietly in your chair with both feet on the ground and your hands in your lap. You can close your eyes if you are comfortable doing so. Allow yourself to feel centered in the chair. Bring all of your attention to the physical act of breathing. Start to notice the breath as it enters your body through your nose and travels to your lungs. Notice with curiosity whether the inward and outward breaths are cool or warm, and notice where the breath travels as it enters and departs.

Don't try to do anything with your breathing – simply notice it, pay attention to it and be aware of it. It doesn't matter if your breathing is slow or fast, deep or shallow. Allow your body to do what it does naturally.

It's normal for your mind to wander during this activity. Part of mindfulness is noticing that your mind is wandering, and gently, without judgment, redirecting your attention back to your breathing.

Now I want to take you into that room with that parent. Visualize going into the room and preparing to have that difficult conversation. Remind yourself where you have that uncomfortable feeling (it's okay if you don't have any particular feeling or sensation). Try to really focus on the physical feeling, where you are experiencing it. Don't try to modify the sensation in your body, just allow yourself to notice it with curiosity.

Are you experiencing any emotions in that room? Sadness, shame, frustration? Try to observe these emotions without judgment and with curiosity, and without trying to change them.

Notice any thoughts that that are going through your mind. Notice them as they change and notice each new thought as it replaces the previous one.

See if you can put words to some of the feelings that come with these thoughts. They may be feelings like sadness, shame, hurt, frustration, loneliness, or fear. Feelings may be difficult, they may be deeply uncomfortable, but they are not wrong or right. They are simply part of your present moment experience.

Ask yourself, are you okay with staying in that room with those people and with those feelings and thoughts? Can you do this without feeling a need to get out of that room or away from those people as quickly as possible? Or without feeling that you have to offer them something that will fix or change their difficult situation?

Finally, bring your awareness and attention back to your breathing for a while, noticing the physical sensation of taking breath into your body and releasing it. If you find yourself focusing on bodily sensations, thoughts, or emotions, gently and without judgment redirect your focus back to the breathing

When you are ready, you can open your eyes and return your attention to this room.

You can now turn your phone back on.

Discussion Questions

You don't have to tell the group the details of the case you were thinking of. What we want to focus on is your own physical sensations, thoughts, and emotions.

1. How did it feel to focus on your breathing at the beginning of the exercise?

2. What physical sensations (if any) did you notice while thinking about this case? (follow-ups if needed): Did you experience tension or tightness in any body parts? Did your heart rate change?

3. What thoughts came into your head? Were they positive or negative? Were you able to observe these thoughts without judgment?

4. What emotions did you experience?

5. How did it feel to return your focus to breathing at the end of the exercise?

What we did today was a very brief mindfulness exercise. Some clinicians find it helpful to be able to recognize and accept without self-judgment the physical signs of stress and anxiety they experience when they interact with patients with a poor prognosis and their parents.

The goal of this exercise is not to change how you feel, but to accept that it is okay to feel that way. Hopefully you can experience and recognize these feelings without feeling overwhelmed or distracted by them.

Cognitive Insight Script

According to cognitive behavioral theory, the way we think can affect our mood. The way we think can also influence how we react to difficult professional situations. We may think in a negative ways or have negative views of ourselves (e.g. "I'm a terrible doctor" "I haven't advocated successfully for this family"), our job (e.g. "Caring for these patients isn't helping them any") and the future (e.g. "I will never be able to help these kinds of patients").

Negative thoughts like these have several characteristics. They are:

- **Automatic**: They just pop into your head without any effort on your part.
- **Distorted**: They do not fit all of the facts.
- **Unhelpful**: They keep you depressed, make it difficult to change, and stop you from getting what you want out of life.
- **Plausible:** You accept them as facts, and it does not occur to you to question them.
- **Involuntary:** You do not choose to have them, and they can be very difficult to switch off.

Thoughts like these can trap you in a vicious circle. The more down you become, the more negative thoughts you have, and the more you believe them. The more negative thoughts you have, and the more you believe them, the more upset you become. It can be particularly disruptive and distressing if these negative thoughts occur regularly when you are caring for patients.

Negative thoughts can be categorized into specific thinking errors such as catastrophizing, overgeneralization, focusing on the negative, or jumping to conclusions about what people are thinking. See the handout for a complete list of types of thinking errors.

Today we will do two activities to identify negative, disruptive thoughts we may encounter while caring for patients: an individual activity and a group activity.

Individual Activity

We will give each of you a card to write on. This card is for you to keep, and you do not have to share what you write with the group.

What is a negative thought that you have personally experienced when providing care for patients with a poor or uncertain prognosis?

You do not have to share this thought with the group, but write the thought down on the card provided.

Next write down the thinking error (if any) behind the thought in that situation.

Now write down answers to some of the questions if possible:

1) What evidence exists against this thought?

2) Would other people accept my thoughts as true?

Though we may believe something to be true, this does not necessarily mean that it is. It is often valuable to see if the facts of the situation back up what you are thinking, or whether they contradict what you are thinking.

3) What is an alternative to this thought?

4) What do I need to think in order to act and feel differently?

Group Activity:

What we will ask you to do today is to think of examples of negative thoughts that might come into come into a clinician's head when caring for a patient who might die or while thinking about whether to refer a patient to palliative care.

1) What are some examples of negative thoughts a clinician might experience when considering whether palliative care is appropriate for a patient?

[Write down examples on board, and go through questions below for each negative thought]

2) What negative characteristics does each thought have from the list (e.g. automatic, distorted, unhelpful, plausible, involuntary)?

3) What thinking errors does this thought show?

4) What are alternatives to this thought?

Suggested Activity to do on Your Own

Every time you have one of these negative thoughts in the following week, use the technique of identifying your thinking error and try to generate an alternative. Or you can identify other negative thoughts that you notice, and complete this activity with those thoughts.

Activities for Codesign Session 3: Role Ambiguity, Collaboration, and System Level Barriers

In codesign session 3, the codesigners participated in two activities with the intention of picking on of the two options to reduce role confusion: addressing knowledge gaps and appreciating the roles of others. The session leader also asked participants to discuss potential system level barriers to collaboration and initiating palliative care. The session leader also asked participants to review materials about capacities and skills associated with collaborating successfully, also based on "TeamTalk 2015-16".[74] The codesign team members were asked to select which of the 3 descriptions of team skills options would be best for their group.

Role Confusion Activity 1: Addressing Knowledge Gaps

One of the most important parts of working together as a team is knowing your own role and the role of others on the team. This is particularly true when the team is dealing with a difficult situation such as caring for a patient with a poor prognosis and deciding whether or not to refer that patient to palliative care.

I am going to give each of you a card. On the back of the card please write the discipline you were trained in. Now think of a situation where palliative care might be an appropriate option for a patient. Then, finish this statement about what skills or expertise you bring to a team conversation about whether PACT should be consulted without specifically stating what your role on the team is. Think specifically of something you can contribute in this situation that other team members might not be aware of.

1. In discussions about referral to PACT, I contribute …?
2. Additional contributions that I could make to caring for these patients that other team members might not know about are …?

Now I will collect the cards, mix them up, and give them out again.

Now I want each of you to read your card aloud and then try to guess what is the role of the person who wrote this card. Then I want you to flip the card over to see if you got it right.

What was surprising that you learned?

Role Confusion Activity 2: Appreciating Others' Roles

One of the most important parts of working together as a team is collaborating with team members from other disciplines. This is particularly true when the team is dealing with a difficult situation such as caring for a patient with a poor prognosis and deciding whether or not to refer that patient to palliative care. You may have had experiences where you recognized and appreciated a team members' expertise that complemented yours and gave you new insights into whether PACT would be helpful for a patient or family.

I am going to give each of you a card. Now think of a situation where the team was struggling to find the right way to support a family and you appreciated the contribution of a team member

from another discipline. Describe what your team member contributed and be sure to write which discipline your team member is from.

I will collect the cards and read some of your appreciative statements to the group.

Role Confusion Activity 3: System Level Barriers to Utilizing all Team Members

Sometimes your colleagues may know and value what you bring to the team, but they may not include you in team or family discussions. Has anyone had this happen?

What kinds of barriers might lead to this happening?

What practices could we adopt to avoid this in the future? Is there a workflow that we could institute prior to an important discussion with a family to ensure everyone who has expertise to offer is present?

I. Capacities for challenging conversations and interprofessional teamwork
(Modified from UCSF TeamTalk 2015-16: Interprofessional Training in Palliative Care Communication)[74]

Capacity	Example Practices
Self awareness	• Pay attention to one's inner experience, including bodily sensations, strong feelings, distractions, comfort or discomfort, judgments, and emotions • resist urge to have your opinion be the only "right" one
Compassion	• In your mind, wish well to the patient, family and to your team members. • You could also verbally articulate to your patient, family and team members that you are working together to find the best plan. • Don't assume you know why someone is saying or doing something, approach it with curiosity
Response flexibility	• Let yourself respond to what is happening in the moment • Don't get too caught up in rehearsing in your head what you are going to say that you miss what is being said • Your contribution doesn't have to be perfectly worded to be helpful to the group
Reflective practice	• Non-judgmentally reflect on your recent experiences: – How might previous experiences affect my communication with this patient, family, or team member? – What assumptions might I have made about this patient/family/team member? – Did anything surprise me? – Did anything interfere with my ability to be attentive or respectful? Were there any points at which I felt judgmental about someone in the room?

II. Responsibilities of All Team members

- Contribute your expertise
  - Share your perspective and skills with the team
- Generosity & Respect
  - Praise your team members for their contributions
  - Assume best intentions for your teammates
  - Invite others to speak
- Discipline & Patience
  - Don't say too much or over-explain
  - Let others speak
- Curiosity
  - Keep returning to what you can learn from your team members.
  - Listen for intent – don't assume you know what they intend.
  - Ask "tell me more about why that is important?"
- Trust
  - Build trust in your colleagues and the team process by using the above and recognizing when your colleagues do the same.

III. Intra-Team Skills for Discussions *(Modified from UCSF TeamTalk 2015-16: Interprofessional Training in Palliative Care Communication)*[74]

Skill	**Purpose**	**Example**
Invite participation	• Draw out critical information and viewpoints • Ensure all key disciplines are heard • Validate others' viewpoints • Make the best use of team skills/knowledge • Build team consensus	"what experiences have others had when talking with the family?"
Friendly question	A respectful way to: • Clarify • Draw attention to an unaddressed area or need • Advocate for family	"Can you explain the thinking behind…?" "What would need to happen for [patient] to reach that goal?" "[Family member] asked me earlier…"
Seek Permission	• Respectfully interrupt and redirect • Seeking non-verbal permission before interrupting	"Would it be OK if I ask a question?" "Can I ask question about something on a different topic?"

Kudos	• Build team trust with appreciation • Demonstrate respect for team members' contributions	"[Nurse's name] really worked hard to make sure that the family got their questions answered."
Yes. And…	• Manage disagreement without negating others' contributions (Using "But" negates everything that came before it)	"I agree that there are many treatment options to explore and I wonder if we might also focus on ensuring [patient's] comfort while we're doing so."
Support to Disagree	• Manage disagreement by acknowledging importance of other position •	"I appreciate your position and can see why addressing these things is important to the patient."
(re)Focus on the patient	• Manage disagreement • Find common ground • Acknowledge shared goal of caring for patient	"It looks like we have different perspectives on this complex issue. What do you think [patient] needs right now?" "I know we're both trying to do what's right for this family."

Activities and Materials for Codesign Session 4

In codesign session 4, the codesigners reviewed case descriptions and materials for two group collaboration activities. The first collaboration activity was a brief activity to occur at the end of intervention session 3 after participants had reviewed the collaboration skills materials. The second, longer collaboration activity (megacode) was for intervention session 4. For both activities, the session leaders asked the codesigners for feedback on the patient cases to ensure that required team discussion and collaboration to reach the best decision.

Group Collaboration Activity

[Have participants pick numbers out of a hat to randomly assign them to 2-3 teams]

After reviewing different skills and strategies that group members can use when discussing difficult cases, we will ask participants to try to use some of these skills in a brief case discussion. Participants will read the case, and then will be assigned to one of the positions.

BMT Case 3b: 14 yo F with MDS s/p BMT
16 year old female with AML s/p MSD bone marrow transplant with busulfan, Cytoxan one year ago. She presented to clinic for a sick visit because she was having easy bruising. Studies revealed pancytopenia and dropping chimerism for which she was able to receive a donor leukocyte infusion. On follow up clinic visit she has evidence of dropping chimerism once again and the donor leukocyte infusion has not been successful.

She has endorsed feelings of sadness that she can't be a "normal" 16yo girl and while she doesn't want to go through another transplant, she is afraid of dying and leaving her mom alone and thus wants to proceed with an unrelated donor stem cell transplant.

You are meeting as a team to decide what should be discussed with her and her family and treatment plan moving forward.

Position 1: Inform the family of the situation. Recommend continuing with curative treatment even if the chances of it working are low.

Position 2: Inform the family of the situation. Explain the pros and cons of continuing treatment with curative intent while still recommending initiation of a palliative care consult for an added layer of support.

Position 3: (if have enough people): Inform the family of the situation and explain why you will be referring them to palliative care to discuss options for focusing on keeping their child comfortable. Emphasize that continued treatment is unlikely to help the child, that they may experience unwanted side effects, and that it may impact their current quality of life.

Neuro-Oncology Case 3b: 5yo F with anaplastic astrocytoma
Patient initially presented at 4yo with early morning emesis and headache and was diagnosed with a focal thalamic anaplastic astrocytoma. She had a subtotal resection with VP shunt

placement and treatment with temozolamide/radiation followed by maintenance chemotherapy. Parents were informed that with a subtotal resection there was a higher risk of recurrence. Still, MRI after three additional cycles was stable and they were very happy and hopeful that she was cured.

She is now 5 years old and is presenting to clinic with early morning emesis and frequent falls. MRI results were concerning for disease progression with increase in T2 flair abnormal signal. Although her course was complicated by hemiparesis, she has had an excellent quality of life since completion of therapy. Her mother is very unsure about how to proceed. You are meeting as a team before a scheduled family meeting tomorrow to discuss what you should discuss with the family and any recommendations the team would make.

Position 1: Inform the family of the situation. Recommend continuing treatment despite concern that the new changes on MRI might be c/w disease progression.

Position 2: Inform the family of the situation. Recommend changing treatment and enrolling on a Phase I clinical trial of a new agent while still recommending initiation of a palliative care consult for an added layer of support.

Position 3: (if have enough people): Inform the family of the situation and explain why you will be referring them to palliative care to discuss options for focusing on keeping their child comfortable. Emphasize that continued treatment is unlikely to help the child, that they may experience unwanted side effects, and that it may impact their current quality of life.

Solid Tumor Case 3b: 7yo with synovial sarcoma

The patient is a 7 year old male with an abdominal synovial sarcoma. He was initially treated with surgery, radiation, and chemotherapy for non-rhabdomyosarcomatous soft tissue sarcomas. While he had a good response to therapy, he suffered from renal and cardiac insufficiency such that he was not able to receive full dose therapy. He relapsed three months post completion of initial therapy with subsequent resection of the recurrent abdominal lesions.

Unfortunately, repeat imaging is again showing localized tumor recurrence. His father wants you to do everything and give him more chemotherapy to cure him. You are meeting as a team first to decide what should be discussed and what recommendations to make to the family at this time.

Position 1: Inform the family of the situation. Recommend continuing with curative treatment even if the chances of it working are low.

Position 2: Inform the family of the situation. Explain the pros and cons of continuing treatment with curative intent while still recommending initiation of a palliative care consult for an added layer of support.

Position 3: (if have enough people): Inform the family of the situation and explain why you will be referring them to palliative care to discuss options for focusing on keeping their child

comfortable. Emphasize that continued treatment is unlikely to help the child, that they may experience unwanted side effects, and that it may impact their current quality of life.

Handling asymmetric information within the team: Megacode (Session 4)

Cases where team collaboration is essential to knowing all of the details related to the patient and their family. Everyone will be given the "summary for all". The rest of the information will only be given to specific team members.

BMT

Summary for All:

10 yo female with history of AML s/p MSD BMT that has been complicated by chronic extensive skin and gut GHVD. Most recently she has been hospitalized with severe abdominal pain and bloody diarrhea in the setting of gut GVHD that is now starting to resolve. She is in clinic for follow up and there are new peripheral blasts on her smear.

Goal:

You have a family meeting scheduled with the family and are meeting as a team to discuss your concerns about how to proceed and what should be discussed with the family.

<u>Information for individual team members:</u>

MD:

Her transplant was complicated by skin and gut GVHD, as well as septic shock resulting in a prolonged ICU stay. She has had trouble weaning off of pain medications secondary to continued pain and she has cardiac dysfunction from her chemotherapy. You are worried about next steps given the chronic skin GVH in the setting of peripheral blasts.

NP:

The patient has expressed to you that her abdomen still hurts but that the pain medication makes it feel better. She has been tired and sleeping more lately and hasn't been able to play with her siblings very much.

The father has expressed to you that he does not like use of medications that cause addiction because he previously had a problem with opioid use and wishes to avoid putting his daughter at risk. He discloses that one of his close friends died of an accidental overdose. He wants everything done to cure his little girl and doesn't want to put her at risk.

SW:

She is from New Jersey and is here with her parents. Her 8 yo sister and 5 year old twin brothers are staying with her maternal grandparents several hours away. In the past several months, the family has only had intermittent short opportunities to spend time together as a family. The mother shares with you that the marriage is strained. Mom is worried that her daughter has been suffering through this therapy and unable to spend any time at home with her siblings to whom she is very close. She is also worried that her other children are withdrawing and acting out at home. She is scared that the patient is having a relapse because she is been so tired lately. She doesn't know if she can go through all of this all over again.

Her father has been consistent with communication to you in expressing wishes for cure and wants everything done to achieve this goal. The father's cousin also had cancer. He thinks it was also a leukemia and it took three years to cure it, but now he is well. He continues to believe the same will be the case for his daughter.

The nurse shares with you that the father becomes angry with his wife and irritable with his daughter when they recommend an as needed dose of pain medication.

Neuro-Oncology
Summary for All:
2 yo female with disseminated ATRT. She is halfway through her therapy and has transferred to you from another institution after a complicated and prolonged PICU course. She is now admitted having increased seizure activity and irritability. Her seizures have been progressively more and more difficult to control in the last two days. Additionally, she also seems to be in significant pain from leptomeningeal disease.

Goal:
You have a family meeting scheduled with the family for tomorrow and are meeting as a team to discuss your concerns about how to proceed and what should be discussed with the family.

<u>Information for individual team members:</u>

MD:
She and her family came to CHOP to pursue further therapy and are hopeful for a cure. Her first cycle of high dose chemotherapy at the outside institution was complicated by a prolonged ICU stay with life threatening complications. Her subsequent cycles have been delayed while awaiting recovery from these complications. CT scan on admission showed no evidence of intracranial hemorrhage. You are planning for an MRI to evaluate for disease progression. In the meanwhile, you are evaluating your options for next steps depending on what the MRI shows.

NP:
Her father does not like use of medications that cause addiction because he previously had a problem with opioid use and wishes to avoid putting his daughter at risk. He shares that one of his close friends died of an accidental overdose. He wants everything done to cure his little girl and doesn't want to put her at risk.

The bedside nurse comes to you expressing concern that continued offer of aggressive treatments for the seizures will result in respiratory depression and are not sure if they are doing right by the patient without further goals of care discussion.
SW:
She lives in New Jersey and is here with her parents. Her 8 yo sister and 4 year old twin brothers are staying with her maternal grandparents several hours away. The family has not been together as a family in several months. Her mother is worried that she is suffering. She is also worried that her 8yo daughter is acting out and starting to withdraw from the family.

Her father has been consistent with communication to you in expressing wishes for cure and wants everything done to achieve this goal. The father's cousin also had cancer. He thinks it was a leukemia and it took three years to cure it, but now he is well. He continues to believe the same will be the case for his daughter.

The bedside nurse shares with you that he becomes very angry with nurses and residents when they recommend increasing its dose for seizure control.

Solid Tumor

Summary for All:
14 yo female with metastatic Ewing Sarcoma who presents with excruciating neck and back pain. She completed therapy three weeks prior. Imaging today is concerning for worsening metastases along her C and T spine.

Goal:
You have a family meeting scheduled with the family for tomorrow and are meeting as a team to discuss your concerns about how to proceed and what should be discussed with the family.

<u>Information for individual team members:</u>

MD:
Her course has been complicated by several unplanned admissions, the last of which included a prolonged ICU stay with life threatening complications. She did not tolerate radiation therapy very well and had several skin burns as well as severe nausea. Based on the location of the lesions you are worried about the possibility of spinal cord compression and respiratory insufficiency with continued progression of disease. You are reaching out to your radiation oncology colleagues to discuss risks and benefits of radiation. In the meanwhile, you are encouraging residents to optimize pain control with opioids.

NP:
The bedside nurse comes to you because she feels that the patient's pain is not well controlled and is wondering about stronger pain medication while awaiting further management.

Her father does not allow use of opioids because he previously had an opioid addiction and wishes to avoid putting his daughter at risk. He shares that one of his close friends died of an accidental overdose. He wants everything done to cure his little girl and doesn't want to put her at risk.

SW:
The patient lives in New Jersey and is here with both of her parents. Her 12 yo sister and 10 year old twin brothers are staying with her maternal grandparents several hours away. The family has not been together as a family in several months because she has been staying locally while receiving intense chemotherapy every 2-3 weeks. She and her family are hopeful for a cure. Her

mother is worried that she is has been suffering through this therapy and unable to spend any time at home with her siblings to whom she is very close.

Her father has been consistent with communication to you in expressing wishes for cure. The father's cousin also had cancer when he was a child. He thinks it was leukemia and it took three years to cure it, but now he is well. He continues to believe the same will be the case for his daughter.

The bedside nurse shares with you that becomes very angry with nurses and residents when they recommend medications for pain control.

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