Overall workshop objectives for trainees

All objectives will be met through didactic, small group discussion, and simulated hands on practice in areas of pediatric primary palliative care competencies related to end of life care.

At the end of this workshop, participants will be able to:

1. Define pediatric palliative and end of life care **(Large group pre brief)**
2. Support a family through a time of diagnostic uncertainty **(Episode 1)**
3. Support a family through an acutely stressful and traumatic event (receiving end of life news) **(Episode 2)**
4. Provide guidance and reassurance about pain and symptom management **(Episode 2)**
5. Engage family members in shared decision making for end-of-life goals **(Episode 2, 3)**
6. Respond to a patient's family's questions and concerns related to palliative and end-of-life care. (Episode 3)
7. Discuss elements of uncertainty with respect to prognosis and illness trajectory **(Episode 3)**
8. Explore a family's psychosocial and spiritual needs in order to support and/or make appropriate referrals **(Episodes 1, 2, 3)**
9. Engage with interprofessional team members in alignment with their roles and skills **(entirety of workshop)**
10. Demonstrate compassionate and sensitive communication **(entirety of workshop)**
11. Engage in reflection and debriefing to enhance wellbeing as a provider experiencing indirect trauma **(post-scenario debriefing and large group debriefing)**

Case overview information for SPs

Medical case and patient/family overview

Joshua ("Josh") is a 5 year old who was diagnosed with high risk neuroblastoma at 2 years of age when he presented with pain, refusal to walk, and increased fussiness. He was found to have diffuse metastatic disease with both osseous and bone marrow metastases. He had a great response to his upfront treatment, which was 18 months of multimodal therapy (including chemotherapy, surgery, radiation, myeloablative chemotherapy and autologous stem cell transplant & immunotherapy) and finished treatment having achieved a complete response and had his Port-A-Cath removed. He is now about 17 months off treatment and was last seen in the oncology clinic 2 months ago at which time he continued to do very well.

He was recently seen for a well-child check prior to starting kindergarten and his family noted he had not been eating as well and just seemed a little off. The provider and her pediatric trainee (you can't remember if it was a student or resident) at that visit were concerned about suboptimal growth, provided some basic nutritional advice and anticipatory guidance related to picky eating, and asked the family to come back in 1-2 months for a weight check. The day before the appointment, the mother called the nurse line saying that a neighbor pointed out that her son looked pale and asked if they could have a CBC done before the appointment, which was ordered.

The patient: Joshua Williams

Joshua is 5 years old. He lives with his mother and grandmother. He was born full-term and was healthy (previously seen by your preceptor at this clinic) until he was diagnosed with neuroblastoma at 2 years of age. He was cared for mainly by the pediatric oncology team during his treatment. He was said to be cured as of 17 months ago, and has re-established care in this primary care clinic. He had no complications following his initial treatment.

Joshua likes playing cars and soccer, watching Wild Kratts on PBS Kids, and eating mac & cheese. He does not like it when he has to take a bath or his 7 year old sister Jada tells him what to do. His mom shares that he doesn't seem to remember a lot about when he was in active treatment, but is pretty cautious in medical settings. She thinks he may remember things that scared him but also probably has good memories of how kind and fun people always tried to be.

The mother: Jen Williams

You have two children, Joshua (you often call him Josh) and Jada. The time surrounding Josh's diagnosis (he was 2 years old) and early treatment of neuroblastoma was the hardest time in your life given his illness, recent separation from your partner, and having two young children (Jada was 4). During his treatment course, you found support in new places, including your mom moving in with you and from all members of the oncology care team and a therapist. You were able to step away from work and focus on your family's needs and be with Josh throughout all of his treatment. The focus during his entire course was cure of his disease, and he had some hospitalizations but never required intensive care unit care. You have never had to make any end of life medical decisions for him or any other family members. Overall, you see it as a hard time you were all able to overcome and feel fortunate everyone is better.

You have now been back to work as an administrative assistant for about a year. You are technically a so-called "single mother" but don't like that label as you feel you have adequate support from your mom (who still lives with you), along with extended family nearby, and a close-knit community at your church. You do have primary decision-making for your children but always respect your mother's perspective.

You shared concerns at Josh's last checkup about him being a picky eater. You were overall reassured by his doctor and your mom and tried to incorporate ideas to help him eat more. At that visit you also met with a social work intern about an application for early childhood developmental resources as he has exhibited some delays in pre-kindergarten level learning readiness.

However, you've been feeling more anxious over the last week, especially since a neighbor commented on him being pale, leading up to a follow-up clinic visit. Yesterday, you finally decided to call and ask for blood work.

The grandmother: Jessie (Jesse) Williams

You have four grandchildren. Joshua and Jada are the only two who live in town. Your partner (Jen's father) died suddenly in a car accident 15 years ago, before you had any grandchildren. You were called urgently to the emergency department where an ambulance had brought him, and he was already dead when you arrived. This was of course very hard on you and your family. At this point you are overall at peace and living with long-term grief. You have not otherwise had to make any difficult or end of life decisions for a family member.

You moved in to support your daughter Jen three years ago surrounding the time of Joshua's diagnosis with neuroblastoma and recent split from her partner. At that time you were the main source of income (you work as an elementary school teacher) and often primarily cared for Jada so Jen could stay in the hospital with Joshua. While Jen does not always parent the way you would, you try to be consistent with her and have maintained a goal to be the kids' grandma. The kids, especially Joshua, see you as their grandma; Jada and you have a very close bond and favorite things to do, as you tried to keep things as happy and normal for her during Joshua's treatment.

You know your daughter has been worried for several weeks now with Joshua not eating as well. You have mostly tried to provide reassurance, especially knowing what you know about preschool kids and their food preferences. However, you recently also got worried when a neighbor noticed Joshua is paler. Jen shared with you she didn't want to be the parent to call and ask for blood work before an appointment, but you encouraged her to advocate and get that information. You also offered to go to the follow-up appointment with her because both of you are worried and you want to be there in case there's bad news.

Logistics

The learners (pediatrics residents, graduate nurse practitioner students, and graduate social work students) are divided into groups of 3 or 4 (rarely 2) for ~3 encounters (1- 10 minutes, 2 & 3- 18 minutes) that build upon one another. As standardized patients, you will portray the patient's mother and grandparent and complete a feedback form after each encounter and provide verbal feedback (~4 minutes). Faculty will observe the encounters remotely and assess the learners' performance. The encounters will be recorded. There will be 3 scenarios with the same group, spanning about a month.

Encounter 1 (10 minutes with trainees)

Location- Primary care clinic

Simulation Environment and Equipment Overview

- Pediatric clinic room
- Vitals signs cart (i.e. blood pressure cuff, etc.)
- Chairs, small table

Family instructions scenario 1

The medical assistant (MA) roomed Joshua. They obtained vital signs and briefly asked how Joshua was doing. You are glad that he gained weight in the 6 weeks since he was last seen. You shared you're concerned about the blood work, and the MA told you they didn't have the results back. You also asked if the social worker was there regarding paperwork you discussed last time. The MA committed to sharing your concerns and request for the social worker with the team. You as the family have picked up on the fact that Josh is being asked to leave the room while the team comes in (a warning shot about the possibility of difficult news).

The medical assistant told you the team will be coming in soon and asked to take Josh to get a sticker and do coloring for a few minutes.

Family's agenda for this portion of the case (you both have the same agenda):

1.) You want to know what is going on with Joshua. Specifically, you want to know if his cancer could be back.
2.) You want to know what each team member's role in this particular discussion (role clarity)/stage of the case
3.) You want to ensure there will be oncology consultation and follow-up (Dr. Sharon Green)
4.) You want to feel supported at this time of re-traumatization and new uncertainty
5.) (You'll want to figure out how to tell Joshua, but in this first part, you're focused on those first 4 needs before being able to consider how to tell him.)

When the whole team walks in:

Jen- "the cancer's back, isn't it?"
Jessie- "why did all of you come into the room this time?"

Support/prompts from family to navigate arc of the encounter

"This is like a bad dream– being back where we were 3 years ago."

"How will we get through this?"
This is a question about your emotions– shock, grief, disbelief– could prompt discussion about what support looks like for you: family, neighbors, church community, Jada's school, etc.

If brought up, you may acknowledge more minor financial complaints (hospital parking, co-pays, etc.) but overall your insurance coverage worked out well during his last cancer diagnosis, so that is not your major focus right now.

“Are you going to call our oncologist?” … “Dr Green… she’ll know what to do.”

If telling Joshua is brought up- “Yes, we’ll figure out how to tell him, but right now we want to know more about…”
“Yes, you can help us tell him, but right now we want to know more about…”

Encounter 2 (18 minutes)

Location- Oncology ward at hospital

Simulation Environment and Equipment Overview

- Pediatric hospital room
- Vitals signs monitor or cart (i.e. blood pressure cuff, etc.)
- Chairs

Family instructions encounter 2

Joshua has been in the hospital for 5 days. He has undergone a lot of different tests, had a port inserted, and started treatment for his recurrent high-risk neuroblastoma. It was found in his bone marrow again as well as in several bones. Overall, it seems like each result that has come back comes along with “this isn’t what we were hoping for.”

It has been really sad to get bad news after bad news. It has been very hard on your family to restart navigating Jen and Joshua being at the hospital and Jessie and Jada being at home. Jen has taken a leave from work. Jessie is still trying to work but has been able to take off time to be at the hospital with Joshua and Jen some days. Extended family and the church community have been helping take care of Jada during occasional evening and weekend visits also. Jada is not currently allowed to visit the hospital because of visitor restrictions.

Joshua was excited about all the new toys and attention and TVs in the room the first few days, but along with all the tests and procedures, that seems to have worn off. Now he says his body hurts multiple times a day, eats very little, and doesn’t want to interact with the staff or you (mom and grandma) much anymore. He finds comfort in his blankie and still wants to watch Wild Kratts all the time.

Overall, you feel supported as a family by the medical team, nurses, social work, spiritual health, and child-family life specialists. It is still simply a lot to manage.

This afternoon the team organized a big meeting. Your worst fear is true: they shared Joshua’s disease can’t be cured. Even though you were both worried this is why they called the meeting, you’re both in shock. Joshua was awake and playing right after the meeting. Jen had a hard time engaging with him and kept getting tearful. Jessie wanted to stay strong for Joshua and Jen and played with him the whole time. A couple hours after the conference and after he fell back asleep you asked the nurse to come answer some questions. You got a few answers, then the nurse said some of the questions would be good for the social worker, and got that person. The social worker just left the room saying they wanted a provider to help answer some of the questions. You are waiting to see who will come into the room now.

Jen- you are in acute grief, it’s hard to sort it all out. You have existential questions (Why would God do this to a child? To me?)

Jessie- you are fearing being abandoned by the team. You overall want to get into action– if this can’t be cured, we want to get out of the hospital, and I want to figure out how to take a leave from work and do this all at home.

Both of you, overall, while you may not be able to verbalize it:
You are sad and fearful your son/grandson will die.
And
You are worried the team will abandon you.

Family’s agenda for this portion of the case (you both have the same agenda):

1.) You want to know what palliative care is; why would Joshua have chemotherapy if his illness is incurable?
2.) Can we go home?
3.) You want to know what each team member’s role in this particular discussion (role clarity)/stage of the case
4.) You want to feel supported at this time of a new, life-limiting diagnosis– you don’t want to feel abandoned by this team. Specifically, Jen is seeking spiritual health support and Jessie seeks help navigating taking a leave from work.
5.) (You’ll want to figure out how to tell Joshua, but in this first part, you’re focused on those first 4 needs before being able to consider how to tell him.)

When the whole team walks in:
Jen- “Thanks for coming back. I’m feeling a bitconfused.”
Jessie- “We just want to be out of the hospital now.”

Support/prompts from family to navigate arc of the encounter

They said incurable but he can still have chemotherapy treatments, we don’t get that. What does that mean?
Are there other options?

They said something about the palliative care team, what is that?

They said something about going home, when could he do that? Who would take care of him? How soon would we be able to go home?

Jen- This is unfair, how could God do this to us?

Jessie- I’ll need to take a leave. I have a meeting with my boss tomorrow, what do I need to ask for?

Encounter 3 (18 minutes)

Location- Pediatric Intensive Care Unit

Simulation Environment and Equipment Overview

- Pediatric ICU hospital room
- child mannequin intubated, sleeping under a blanket
- Mechanical ventilator
- Vitals signs monitor
- IV pumps
- Chairs

Family instructions scenario 3

Joshua was discharged from the hospital a few days after the care conference where you got the news about incurable disease and you've all been at home about a month now. He has been on home hospice with ongoing oral (by mouth), palliative chemotherapy (for his symptoms only). It has been good to be at home this past month, so you can all be there together. Jessie is still going to work most days, and Jada has been in school.

Joshua's symptoms have progressed pretty quickly, and he seems to need tweaks in his plans and medications every few days. At first it was very overwhelming, but you have felt very supported by the hospice and oncology teams.

At first when you got home Joshua ate and drank some, and you decided to support him with a feeding tube from his nose to his stomach ("nasogastric" or "NG tube"). Now he hasn't even wanted his favorite mac & cheese for about 2 weeks. He complains of stomach aches some days, which can often be helped with smelling an essential oil on a cotton ball and also sometimes zofran or lorazepam.

He spends a lot of time sleeping. When he is awake he is often in pain, for which he is on methadone and receives additional morphine doses when needed, which has been multiple times per day the past week or so. He does still get up and play with his sister once in a while and still always asks to watch Wild Kratts.

A few nights ago, Joshua started having a persistent nose bleed (he hadn't really had this before), and you called the hospice team. The home hospice nurse helped with some ideas to stop it and keep him comfortable overnight. At first it worked for a few hours, but then the bleeding started again. The home hospice nurse then visited and noted a persistent nose bleed, bruising, and fast breathing. After a discussion, you decided that without knowing why he was having nose bleeding, you wanted to figure out why this was going on and what could be done to stop it. You called 911, and they took Joshua to the hospital. Jen met Josh and the ambulance there, Jessie stayed home to be there when Jada got home from school.

In the emergency department, Joshua kept having the nose bleed, and his fast breathing was getting worse, and they put a big mask (“continuous positive airway pressure” or “CPAP”) on his face. Tests showed his platelet level (helps with blood clotting) was really low. He was quickly admitted to the Pediatrics ICU. Joshua looked very scared the whole time. The next few hours were a blur. His breathing didn’t get better with CPAP, and the team said he needed a lot of oxygen. They talked with you about options about what to do next, with Jessie on FaceTime, and you all decided to put in a breathing tube and put Joshua on a breathing machine (ventilator) in hopes that his breathing failure would be reversible with treatment of the blood not clotting and low platelets and that he could have nasal packing to stop the bleeding.

In the few days since then, everything seems to keep getting worse. The nose bleeding slowed down, but never really stopped. Josh has needed almost continuous transfusions of all the different blood products. The team believes he has started having some bleeding from within his lungs (“pulmonary hemorrhage”), and his lungs have gotten sicker and they say “stiffer,” so he’s needing more and more help from the ventilator. He can’t be on feedings anymore with how sick he is. He has barely been awake because he keeps showing signs of pain and also sometimes they say is “fighting the ventilator.” He is on a lot of medicines for his pain and agitation. The first day he seemed comforted when Jen sang to him, but now he does best when it’s quiet in the room. He does seem comforted to have Jen or Jessie gently touching him or holding his hand.

You both have had conversations that you never want him to suffer too much, and worry that’s where he’s at now.

At rounds today the team seemed most worried that Joshua has not peed for over 24 hours, and the team mentioned he could need dialysis. They have also brought up transitioning to comfort care and stopping all the medical interventions that won’t be able to cure his disease. Jessie was on FaceTime during rounds so she heard all of this but had a hard time discussing much with Jen and didn’t ask the team any questions.

A few hours later, Jessie is now in the room with Jen. Both share worry about how ill he is and how much pain he is in. He is very puffy/edematous. Anytime he’s a little bit awake his heart rate goes up and he scrunches up his face. The team has been giving him more and more pain medicine. The nurse shared that sometimes patients need a paralyzing medication when they get too agitated, and that sounds really scary.

You both start asking the nurse questions about what would happen if the breathing tube was taken out. The nurse has a brief discussion with you, and you feel supported that this would be an ok plan for Joshua. They state they will get one of the providers to talk more about that.

You have both accepted that he is nearing the end of his life.

Please note, it is common that parents do not even know they are accepting imminent death, but that the care team notices a difference in what questions are being asked/non-verbal cues (For example: What would happen if the breathing tube came out? How much longer can he live like this?) indicating a move toward acceptance.

<u>Family's agenda for this portion of the case (you both have the same agenda):</u>

1.) How long will he be alive without the breathing tube?
2.) Will he suffer with the breathing tube out?
3.) What medications will help him? Can he get "too much?"-- Will the medications kill him?
4.) You want to know what each team member's role in this particular discussion (role clarity)/stage of the case
6.) You want to feel supported at this time of his dying process
7.) (You'll want to figure out how to tell Joshua and Jada, but in this first part, you're focused on those first 4 needs before being able to consider how to tell them.)

When the whole team walks in:
Jen- "Thanks for checking in. Josh just can't get comfortable."
Jessie- "He's not going to live much longer is he?"

<u>Support/prompts from family to navigate arc of the encounter</u>
Josh is hurting more and more. I think his morphine drip has been turned up 3 times today, and now the nurse said something about paralyzing him. We don't want that.

We came here to see if you could fix Josh's nose bleeds, not only has that not worked, everything else keeps getting worse, too.

I'm worried Josh is suffering.

We talked to the nurse about taking the breathing tube out. If we do that, how long might he live and what medicines would he get?

Is there such a thing as too much morphine? …. (could all the morphine kill him?)

If asked:

- About who else you want present during this discussion
    - Thanks for asking, this is good right now. We do want to see the oncologist again if they're available this evening.
- About dialysis
    - Would that fix his pain and his stiff lungs?

  - We don’t want something that wouldn’t fix the rest of this.
- About Jada being there
  - Yes, we would want Jada there. The Child Family Life Specialist has been really helpful for Jada, could we ask her to help with that again?
- About spiritual health
  - Yes, we want the chaplain there.
  - Yes, we would want our own pastor there.