Subtitles and transcriptions

Palliative medicine in paediatric oncology

Dr Baker: Hello, friends. Great to be with you today. This is very exciting. Thank you so much for the opportunity and I'm hoping that we'll have a chance to learn much together. So, as we get started today, I'm very grateful to actually share and be here with Dr Levine. So, this will be wonderful. And first off, know that you can ask questions and post those, and then, we'll have a good amount of time at the end where we can kind of discuss these issues and talk through them. And we're going to be discussing the strengthening of paediatric palliative care as a component of comprehensive care, specifically, in the context of paediatric oncology. And before we get started though, I always love to start with thinking about why we do what we do. And the reason we do this work is our precious patients and their families. And I want to share a story with you about Jessica, Shadow, you'll see Dr Levine in this video, and about our team, and kind of what all palliative care is about. And I introduce you to Jessica now.

- When I think about Jessica, I am immediately reminded of her smile. You would walk in the room and right away you would know what her mood was. And boy, when she was in a good mood, that smile would light up the room. And boy, when she was not, she would let you know.

- You couldn't meet Jessica and not remember her. She loved the staff, she loved entertaining. She knew she had a gift for making people feel good. And she loved to use that gift.

- She was always full of life. She loved to joke. Oh, she was a Florida Gator fan. For the art teen show, she made a poster with the Florida Gators that was chomping up the cancer.

- She believed in her heart of hearts, as did her parents, that she would absolutely be cured. And it was with that spirit, that spunk, that larger-than-life attitude she approached every day. Then when the tumour started coming back, it just came back raging. At that point, there really was very little that we could do to control it. Certainly not cure it.

- As it became more and more obvious that she wasn't going to be out of the hospital for the remainder of her life, it was all about how can we make these days brighter for her.

- Jessica asked if she could have a puppy from the Make-A-Wish organisation. Having a puppy in an inpatient setting is not a simple feat.

- Anytime you enter an animal into this environment, there are so many things that have to be done.

- We can't just break every rule and say, "Okay, well, let's bring the dog in."

- We have to think about people with allergies, people who don't like dogs.

- The fact that we have other patients here, too.

- Where's the dog going to be? Where's he going to stay?

- Who's going to be responsible for the dog?

- But with all that consideration, how can we make it happen?

- Just to make that one event happen, so many people have to be involved in that.

- No matter what the pet control, nursing, environmental services, security, everyone gets together and we come with the blueprint. It was our job to make sure we were ready.

- We went over to the ALSAC Gift Shop and we found these flags that go on the car. We bought one of those. I took it home and designed it to make it into a vest.

- When he came in the door, his tail was wagging, his nose was up in the air, didn't show any signs of anxiety. Once we saw the personality of the dog, we knew that he was going to be a good fit. We knew that everything was going to be all right.

Dr Levine: Shadow came and had his vest and had his badge and came through so smoothly through security and made his elevator ride up to the floor and enter Jessica's room.

- They take Shadow over to the bed and she was kind of groggy. And she wakes up and she says, "I love you." And she touched his head and then he lay down.

- The initial meeting between the two of them was just like it was just supposed to have been that way. It was just amazing.

- She was so excited and the room was so full of joy.

- She was going to be able to sleep that night with that one major dream fulfilled.

- It was sort of this triumphant moment of all of these things that we've done, which may seem minor, all in together in this one moment where you realise that everything was worth it. To give her this incredible wish come true at the end of her life.

- Shadow made a huge difference. I mean a huge difference in Jessica. She suffered tremendously and Shadow would crawl next to her and be a source of support. And so, seeing the difference that Shadow made, you immediately knew that it was not only the right thing to do, it was the perfect thing to do.

- It's hard as a physician, as a scientist, to sometimes say that there are limits to what we can do with the tools that we have. Shadow was actually almost like part of the medical team. He was able to help us give her some of that comfort and achieve more than what our medicines could offer.

- Jessica knew that she was dying and she wanted to leave her parents something that they could tangibly have of hers, and that was her wish.

- Shadow is playful. He loves to play hide and seek. He loves to chew on empty water bottles and make them squeak, and run and slide, and it makes him laugh. There's a lot of Jessica's personality in Shadow.

- It's hard to describe the love that was in the room, but you could see how much it meant to Jessica and you can see how much it meant to her parents.

- I really think that that's what this place is all about. That's what St. Jude is all about. It is certainly about finding cures and saving children, and that has to be what we're emphasising. But at the same time, it has to be about making every day the best day it can possibly be for every child. In this case, the way to do that for Jessica was by helping Shadow come and be a part of her life. Being a part of her family for those last days of her life made all the difference, and I'm so grateful to have been a part of it.

Dr Baker: So, thankful we got to share that story with you about the remarkable Jessica and her family and Shadow. Our hopes for today are to discuss paediatric palliative care as a response to suffering. I'm going to talk about that and going to try to promote multidisciplinary collaboration. No one clinician can do this work. And then, I'm going to talk specifically about some strategies for paediatric palliative care integration. First, I have to introduce you to my teams, and so, you will get to meet Dr Levine here shortly, but she's in this picture in the upper corner, and our team is called the QoLA team. I'm actually sitting here surrounded by QoLAs. We are the Quality of Life for All team. And when you think about quality of life for all, it's really for every single child. And so, you know, when you think about palliative care, it's for all children. And when you think about palliative, the word actually means to cloak or to cover. And so, I like to think about this extra layer of support, like the ugly holiday sweaters that me and my kids are wearing there in the middle. But the word that really means a lot to me, and I actually did a TED talk on this here in Memphis, and that's the word compassion. And when we think about compassion, this is a really important word because it literally means "com", with, "pati", to suffer. It literally means to suffer with our patients and families. And that's what we in palliative care are called to do. And when you think about kind of the approach to palliative care, sometimes people struggle with how do you talk about it. I mean, what is palliative care? Well, I'm going to make it very simple for you right now. Simple for all of us. I'm an oncologist. And so, when I think about the enemy, my enemy, as an oncologist, is cancer. And oh, I want to beat cancer. I want to push it back. As a palliative care doctor, the enemy is suffering. And so, I want you to think with me and to realise that suffering is the disease that we attend to in palliative care. And you can see this Edvard Munch picture here, and it's called Scream. And I put this up because I got to visit it this year and I was doing a talk very similar to this in Oslo where the Munch Museum is. And so, but suffering is the disease we attend to in palliative care. And Eric Cassell states that suffering is a specific state of distress that occurs when the intactness or integrity of the person is threatened or disrupted. It's very personal. As you can see, completely individual. Even if you have the same input, suffering is experienced different by individuals. And Dame Cicely Saunders talked to us about the concept of total pain. Well, I want us to think about the concept of total suffering. And when we think about total suffering, there's certainly pain and physical symptoms, but there's also psychological and social issues and cultural and spiritual. And this concept of total suffering is in the context of the family. And when you think of the family, it's amazing because the family integrity is threatened. Just as Dr Cassell mentioned, it's a threat. And there are visible threats that all of us can see with our eyes, things like life-threatening illness or physical symptoms, but there's all these invisible threats. And Dr Joanne Wolfe has shared this slide so that we can talk through it. There are these invisible threats like these disruptions to normal life, emotional symptoms, or whatever it is that that patient and family says they're suffering from. And that suffering, we have to then think about targeted interventions and global interventions. And there are always things that we can do to help the family find their new normal or their new family integrity. As we've said at the beginning, please, you can click on the Q&A questions or send any questions by chat if that would be helpful for you as well. So, when you think about palliative care, I want you to recognise that palliative care is a holistic approach. In fact, it aims to address that total suffering and it's clearly proven to improve quality of life. It's clearly proven to improve psychosocial outcomes, and it's also clearly proven to improve caregiver burden. It even can reduce cost. The World Health Assembly states and has acknowledged that palliative care is an ethical responsibility of health systems, and it's the ethical duty of all of us, healthcare professionals, to alleviate pain and suffering, whether that be physical, psychosocial, or spiritual, irrespective of whether the disease or condition can be cured, and that end-of-life care for individuals is among the critical components of palliative care. But it is not what palliative care is exclusively about. I feel so grateful because I was able to go to the United Nations and advocate for palliative care to be included in UHC, Universal Health Coverage 2030. And palliative care is included as a component, a key-component, of universal health coverage. In fact, what we all have to recognise is that access to high-quality palliative care is a fundamental human right. Now, as you think about palliative care integration, I want you to realise that there are three really vital tools that you have to bring to the table. So if you're like, "Goodness, I want to do a better job with palliative care, what is it that I have to do?" Well, the first thing you have to do is you have to use your ears. To listen is to continually give up all expectations and to give our attention completely and freshly, to what is before us, not really knowing what we'll hear or what that will mean. In the practise of our days, to listen is to lean in, softly, with the willingness to be changed by what we hear. The second point, gets to that one, it is willingness to be changed by what we hear. We have to have this open heart that is full of compassion. Remember, compassion means to suffer with. If we have a closed heart, if we have a hard heart, we aren't going to be able to do that. And the third key is the team. And if you really are functioning as a team, deliver that holistic care. And really, in the context of palliative care, it takes a multidisciplinary care team. We have to look at things. You can see here, there's a primary oncologist, a social worker, an oncology nurse, a case manager, palliative care physician, psychologist, child life specialists, all of these working with that patient and family, we have to work with them and really recognise how vitally important multidisciplinary care is. Additionally, we have to realise that, here, in paediatric palliative care, we need to involve the child. Now you may be watching this from a place that culturally you might just say, "Oh, we don't do that." "No, we don't do that." Whatever you do, just try to take it one little step further. How can you better engage that child in the process? How can you bring that adolescent more into the process? And what you'll realise is that as you take these little steps and as you bring them in more and more, they will deeply appreciate it and the care you provide will be better. Additionally, we have to realise that communication is vital to everything we do. And so, we have to understand that our words matter and that communication is the procedure of the hospice and palliative medicine physician. In fact, Eric Cassell again said, "Similar to scalpels for surgeons, words are the palliative care clinician's greatest tools. Surgeons learn to use their tools with extreme precision because any error can be devastating. So, too, should clinicians who rely on words." Or this remarkable bereaved parent that I've spoken with many times, "The way you tell the truth to families makes a huge difference. If you know the person, think about knowing the person, relationship, if you know the person that's coming in there and they're telling the truth, as hard as it is, but you know they care about you, relationship, you know they care about you and they love your child, it's okay. As hard as it is, it's okay and it makes all the difference." So, communication, it's a two-way street. It both helps build relationships, and by being built on relationships, it allows you to communicate better. So, when you think about building relationships, you have to realise that communication involves providing validation, making decisions, enabling family self-management, exchanging information, which is what we mostly think of, but we also have to manage uncertainty, respond to emotions, and support hope. And as we do that, we will build relationships and we'll get to just as that parent told us before, right here, but you know they care about you and they love your child, it's okay. It's about that relationship. Now, this is tough. This is tough work. We really have to be dedicated to discovery, moving these things forward, committed to caring, making sure that we are dedicated to healing. And when you combine these two together, you can think of this remarkable person, Danny Thomas. And we work at a hospital here in Memphis, Tennessee called St. Jude Children's

Research Hospital, where Danny Thomas helped establish this place more than 60 years ago. And as you think through the remarkable commitment to curing cancer and also, the remarkable commitment to healing, the incredible amount of suffering that is involved, I'm so grateful to do this work here. So, when you think about integrated palliative care, I need you to realise it's not like they are ready for palliative care now. No, no, no. Palliative care is integrated throughout the entirety of the cancer journey. And we're going to talk some specifics about this so, we can make sure that you understand this. But basically, recognise that palliative care is integrated throughout the entire thing. And the WHO states that there are these key pillars in the childhood cancer pathway. And you see it, there's early detection, diagnosis, treatment and palliative care, as a core pillar, looking at multidisciplinary care, disease-directed therapy, supportive care, and palliative care. It's critical, it's a vital component of childhood cancer care. And you can see here in this bow-tie diagram, pain and symptom management care, rehabilitation, survivorship, palliative care, all of these are really coming together, making sure that palliative care is integrated right from the beginning. The conceptual model of building a palliative care community and building this into the infrastructure of policies, it starts here, it's provision of palliative care at an integrated health service level. We have to realise there's a use of essential medicines and education and training. There is a bottom floor of research and that is also then supported by health policies and empowering people and communities. And you see at the middle the people with palliative care needs. So, this model is one that we have to realise, we have to look at all aspects of this house as we build up around these families. Here at St. Jude, when we think about integrating, we have an approach that we call the embedded QoLA, the embedded quality of life for all clinician. And we think about points at diagnosis, disease evaluation, crises, relapse, end-of-life care, and bereavement. And we think about how can we best support those through standard operating procedures, through clinical service provision. And the way that we really think about this is with this three-tiered model. And this three-tiered model allows us to think about on-demand delivery of services at the very top. That's a consult-based service. Specific populations. Dr Levine, who leads our bone marrow transplant integration, she'll talk with us more about this during our conversation at the end, our question-and-answer session. But we need to integrate and become a part of these high-risk teams. Become a part of the care, a routine part of the care, not a consult-based approach, but a part of the routine care. And then, we have to help make the institution more palliative friendly, and make sure that coming at that institutional level, that everybody's becoming better at communication, becoming better at symptom management, and that there are education policies and resources that are provided at the hospital level to make sure we're addressing all these issues. Well, at the intersection, this is really paediatric palliative oncology and that's what we're talking about. This overlay of this diagram. And we even have a training programme here at St. Jude to think about this. And when you think about this integration, one of the questions you should ask yourself is, does integrating palliative care make a difference? And a systematic review from one of our amazing researchers here, Dr Erica Kaye, demonstrated that, yes, it does. That as you think about palliative care, subspecialty paediatric palliative care, the services are increasing. And there's significant improvements in children's quality of life and they have fewer symptoms. They're also more likely to have a meaningful moment at the end of life. Parents are more likely to state that the child's dying has been in a good place, and they also receive less intensive care. But that less intensive care and fewer intensive procedures is not associated with shorter life. Additionally, they have improved family satisfaction and improvements in caregiver burden. And caregivers stated that doctors and nurses were more likely to listen to them if a subspecialty paediatric palliative care team was involved. So, I think we can really begin to answer the question. Yes, integrating palliative care does indeed make a difference. So, to become extremely practical with you and just to think about states of integration and points across a timeline, when you think about this, there are predictable opportunities to initiate paediatric palliative care tasks. Now, these tasks, as you think here, there's healthy functional status over time, and when you think about A, you can think about, oh, this patient was just newly diagnosed, there's pain and symptom management issues. They have to cope with this new diagnosis. There's collaboration and communication with the multidisciplinary team members. There's likely family and sibling distress. So, these are things that we can predict and we can think about. And when we think about this, we can then also begin to plan for recovery and accommodating to a new life where there can be lingering symptoms and coping with the new normal. We have to help coordinate care. The very complicated and messy medical system that they have to navigate is very difficult. Families frequently grieve the loss of their well child and there could be anticipatory grief over change in the family, suffering. There certainly could be sibling issues as we stated before. And then, when we think of points of acute decompensation and unexpected recoveries, we have to think about pain and symptom management. We have to think about decision-making and goal-setting. We have to think about comfort-related interventions, care coordination, and multidisciplinary support. There could be a point of slow or precipitous decline preceding end-of-life. And as this is happening, we have to help families cope with the declining condition, we have to make decisions regarding invasive technology, we have to make sure that we are supporting self-determination for both the child and for the parent, we have to have pain and symptom management expertise integrated to make sure that we're working in the midst of this really difficult time to ensure that a patient's pain and symptoms are well treated. There could be tremendous sibling and family distress during this time and we have to anticipate grief and bereavement needs. And then at the time of death, when we think about this, we have to have this death planning and we have to make sure that we're not just doing this reactive. We have to plan in advance. We certainly have to verify decisions regarding resuscitation and we have to be providing intensive symptom management. In fact, at this point in time, if patients have significant suffering, we can predict that the parents will have worse bereavement outcomes. So, please, do a good job during this time. There also is, of course, increasing family and sibling distress and we have to provide care of the imminently dying patient as we also anticipate bereavement issues. Now, for those patients that don't die, they move into the community into a period of survivorship. And we also have to help them. We have to maximise recovery and help them optimise function, and we're monitoring them for late effects. And one thing that you might predict, as you might say is like, "Well, how does a subspecialty paediatric palliative care team do all of that?" Well, I don't think we should. I think that reality, there needs to be a primary palliative care approach and a subspecialty palliative care approach. And we think about these subspecialty situations, we are very needed in acute times of decompensation, we're very needed as patients are approaching end-of-life, and all of this works much better if we meet families earlier and established relationships. But the reality is, when you're thinking about primary palliative care, we're looking to integrate at this bottom level. We're looking to make sure that that bottom tier, these institutional initiatives that we're training all of our nurses to make sure that nurses have integrated palliative care training, and that we've done that here at St. Jude. All the inpatient and outpatient nurses have received 25 credit hours in training. We think about policies and making sure that there are policies for appropriate pain management issues. Admission into our QoLA comfort suite. We have a end-of-life care suite on the wards. And so, we have to think through those. That's where Jessica was, she was staying in that suite. So, when we think about all these issues, there are predictable points and predictable points of integration that we can all think about. And I want to encourage you to involve palliative care earlier, subspecialty palliative care teams earlier. The other thing that I want to tell you is sometimes people are like, "I'm not equipped to do this work. I don't have enough training." Well, I just want to talk to you a little bit about the power of acknowledgment and the power of human connection. And you can make a profound difference in the life of your patients and your families simply by being there for them. And this is a powerful video to reiterate that.

- So, what do we do about all the pain we see in the world? All the pain we feel in our own lives? And why does it seem like our best efforts to help somebody feel better always backfire? I've been studying intense grief and loss, baby death, violent crimes, accidents, suicides, and natural disasters. And I've learned something really interesting. Cheering people up, telling them to be strong and persevere, helping them move on, it doesn't actually work. It's kind of a puzzle. It seems counterintuitive, but the way to help someone feel better is to let them be in pain. And this is true for those giant losses and the ordinary everyday ones. Educator, Parker Palmer writes, "The human soul doesn't want to be advised or fixed, or saved. It simply wants to be witnessed, exactly as it is." He's talking about acknowledgment here. Acknowledgment is this really amazing multi-tool. It makes things better even when they can't be made right. For example, somebody's struggling, their baby died or there's been a bad accident or their mom got sick and they're just sad. It's way more helpful to join them in their pain than it is to cheer them up. But here's what we tend to do instead. "You have two other children; you need to find joy in them." Or, "You know what you need? You just need to go out dancing and shake it off." Or, "I felt really sad once, did you try acupuncture?" We're not really sure what to do with someone's pain, so we do what we've been taught. We look on the bright side. We try to make people feel better. We give them advice. It's not like this is nefarious. I mean, we try to cheer people up because we think that's our job. We're not supposed to let people stay sad. The problem is you can't heal somebody's pain by trying to take it away from them. Now, acknowledgment does something different. When a giant hole opens up in someone's life, it's actually much more supportive to acknowledge that hole and let pain exist. It's actually a radical act to let things hurt. It goes against what we've been taught. In order to really support you, I have to acknowledge that things really are as bad as they feel to you. If I try to cheer you up, you end up defending yourself and your feelings. If I give you advice, you feel misunderstood instead of supported and I don't get what I want either because I wanted you to feel better. It's pretty rare that you could actually talk somebody out of their pain. Rarely does the admonishment to look on the bright side, actually, heal things for someone. It just makes them stop telling you about their pain. It's so tempting to try to make things better. When somebody shares something painful, it's much more helpful to say, "I'm sorry that's happening. Do you want to tell me about it?" To be able to say these hurts, without being talked out of it, that's what helps. Being heard helps. It seems too simple to be of use, but acknowledgment can be the best medicine we have. It makes things better even when they can't be made right.

Dr Baker: All of this comes, this acknowledgment and the ability to make an impact there comes because of a relationship that we establish with our patients and families. So, as we close, I just want to remind you that paediatric palliative care, high-quality paediatric palliative care is a fundamental human right. I would hope that you could use your tools, your ears, your heart, your team, to make sure that you are integrating palliative care. Know that communication is the cornerstone to being a great clinician. Whatever type of clinician you are. And that integrating paediatric palliative care improves outcomes. So, make sure you're thinking of these predictable opportunities for integration. And as you're thinking of integration, think about that three-tiered model, especially, that second tier. I think that second tier can make such a profound difference. And Dr Levine's going to talk to us about that in just a minute of integrating into, in her case, the bone marrow transplant team she's done so beautifully. Please, recognise the power of human connection and the power of acknowledgment. It makes such a profound difference even in symptom management. You can help patients cope with their symptoms by being present with them, by acknowledging them, by recognising that they are suffering and sitting in that suffering with them, truly providing compassionate care, com pati, suffering with them. And please, also recognise that this is so, so difficult. That we can't do this alone and that we have to take care of ourselves. Because if we don't take care of ourselves, we won't be able to take care of our precious patients and their families. And as we close, I want to invite you into our global palliative care community. Please go ahead and take a picture of this. I'm going to take a picture of this to make sure right now that it's up and running, and yep, it is. It's up and running. It will send you to a form and you can go ahead and sign up for email notification from us of upcoming educational activities. We have many resources that are there, part of this community. We have a blog. We also even have many past educational opportunities that have been recorded there, and we'd love to have you. And so, we have plenty of time now for discussion and questions. And so, we just would remind you to please go ahead and click on the question-and-answer session, or you can send your questions and comments in. And again, I'm so grateful to be here with my partner in crime, with Dr Levine, who has done this work with me. We've done it together for a long, long time. And so, Deena, having you here as the discussant is such a joy and I'm so grateful for this opportunity that we've had together.

Dr Levine: Thank you so much, Dr Baker for that phenomenal presentation. And I am not seeing any open questions or chats at the moment. And so, I just encourage everyone, if you have any comments, questions, anything you want to share, please go ahead and do use the chat or the question functions and we'll be happy to address those. In the meantime, I want to follow-up on something that Dr Baker mentioned, which is our model of integration that we developed here at St. Jude for our transplant patients. And really, it came about over a series of years where we had very few palliative care consultations in the bone marrow transplant world, which is sort of not unusual, right? For very high-stakes curative-intent therapy, it used to be thought of, and in some places still is, as very much mutually exclusive where if you're going into a bone marrow transplant, you would not be considering palliative care in that sort of treatment paradigm. And yet, what we found was we had more and more over the course of a couple of years, palliative care consultations. And so we were sort of called into the office of the chair of transplant who said, "What percentage of my patients are you seeing and what percentage of your service is that?" And you know, when we were looking at it, it was actually quite high on both ends. And so, what he said to us is it's time to stop dating and talk marriage. How can we really join our teams together and how can we fully integrate your services with our patients? And, you know, this was such a golden opportunity. It was absolutely what we wanted to do and we had such a tremendous opportunity because we were finding ourselves in a position where there was an investment and buy-in from the transplant team that this would be helpful for all of the patients. And so, we worked together to develop a tiered model of palliative care consultation for all transplant patients, initially all allotransplantations, and then, we added auto transplantations and cellular therapies as well. We also see patients who are receiving CAR T therapy or even gene therapy. And what we found is that we could make a very structured 30-minute initial palliative care consultation for all of these patients in their pre-transplant, pre-evaluation period. And by doing so, we would start to understand who these patients were, what they valued, what their goals, hopes, and worries were. And that really does start to build that relationship that Dr Baker talked about in terms of being very foundational and very important for patients and families. Because if you know them and you're not a strange face, there's not a pushback to your presence and you already have that relationship built, so that if there are difficulties that arise, whether it be symptom management difficulties or really bad prognostic, difficult discussions and decisions, you already have that foundational relationship built. What it also helped us with was what we sort of call proximity. We rounded with the team very frequently. We met with the team at the time of the pre-evaluation meeting. We have this pre-evaluation meeting where all information is discussed and presented and all relevant teams have a chance to give input. And so, we actually became a part of that decision-making process to bring patients to transplant. Had that initial meeting before the patient ever came to transplant, really had a seat at the table at some of these high-level discussions, finding ways to both support families and help them make treatment decisions and give them options that would be very helpful. And we found very quickly that there were patients who may not have been able to come to transplant and get this really important curative option if we had not found ways to support them with a lot of psychosocial services and other supportive care options, which in our field is, you know, it's really a lot of what we do is trying to find out-of-the-box ways to support patients and families. And so, there were patients who got to transplant who maybe would not have gotten to transplant otherwise if we did not have this integration model. The other thing we started to find is we got involved with patients who we really needed to have that relational foundation, who we otherwise would not have been consulted. And so, one of the first patients that we met in this integrative model of palliative care had actually, a really good great sibling donor match for a very straightforward indication for transplant and a very good prognosis. And unfortunately, she developed a toxicity from therapy and had a cardiac failure. And so, this was a patient who went through a very trying time and we were able with that relationship that we had already built, having met this patient and followed this patient on a regular basis from the time she was admitted for transplant, we were able to support them through a really difficult time and through her end-of-life period, which unfortunately came very quickly thereafter. And had we not been consulted in this integrated model of palliative care and transplant; we would not have been involved at all. And so we were able to support patients, number one, to get to transplant who may not have otherwise gotten to transplant, and we were able to support patients who would've gotten to transplant but would've had these very difficult toxicities, complications, and even bad outcomes without necessarily having palliative care till very late in the game, if at all. Another thing that we found was that in following this model where we met the patients in the beginning and then followed them through transplant and met very often with the teams, is that we were able to find symptoms that were not easy to manage or not well-managed and we were able to think outside the box with some of our extra training and symptom management to try and better control those symptoms. And so, we found that there were patients whose, let's say, nausea was very poorly controlled or would've been very poorly controlled without that extra-layer of expertise and extra-layer of support. What we then found after that is very soon into this model of integration, we found that not only were the patient's symptoms better controlled, but that we started to realise that more patient's nausea was better controlled because all of them now had some of these out-of-the-box interventions as part of their upfront care. And so, there were practice-changes that were system-wide that the team really integrated into their daily practise without needing our subspecialty expertise layered on because they had learned from some of our techniques and some of our expertise to then implement those strategies right away in an earlier phase so that patients didn't get to the point of needing subspecialty symptom management. And so, you know, again, we found that we had a seat at the table, we had proximity with the teams, we met more patients earlier on, built these relationships, and we found that patients and families were exceedingly happy with this. Especially, in the very beginning when we started doing this, we had a couple of patients who it was not their first transplant, so this was transplant two, three, and they said, "Why now? This is a bad sign that we're meeting you now." And those same patients, after some period of time, building this relationship and working with them said very quickly, "I am so sad we didn't have you through transplant one and two or three, right?" And so, it became very clear that this was something that was needed and that it removes that barrier, that sort of barrier of I know who you are and I don't want you coming into my room or into my care or into my life. And there are just a lot of barriers removed when you have a fully integrated tiered based model like we developed and that you are able to meet patients and families and help at all different levels. There is now a question in the chat, and the question is, do you adapt your procedures to cultural attitudes of some families, lower dose, not telling the truth, et cetera?

Dr Baker: Mark, thank you so much for that question, and Dr Levine, thank you for that fantastic explanation of that second-tier of integration. Mark, just as a quick aside, I'm going to speak to three papers that I'm putting into the chat. The first one was a paper that Dr Levine led, which is about the integration of palliative care into that second-tier that layer with our bone marrow transplant group. The second paper is the paper that I alluded to with the pyramid. And the third one here is a really helpful communication review, and it's a review of kind of communication techniques to use in oncology, and Mark speaks to this third point there that you have of not telling the truth. So, culture is vitally important. And it's really interesting because I think when most of us think about culture, we think of like a category of patients and we think of a category of society and we're like that group, you know, looks at things in this way. And the reality is every family has a very unique culture. Every patient has a very unique culture and cultural experience. And so, our approach we try to take is one of incredible curiosity and deep humility. One where we ask many questions about particular needs that may arise, including dietary needs or needs-related specifically to end-of-life care or otherwise. Some of those, Mark, relate to how much to involve the child in the process. We do have data that shows that if the children are not involved, then we feel like, and if parent feels like maybe they should have been, that regrets can be involved in that. But most of those studies are done in European contexts or here, in the United States. And so we don't have a lot of data on these issues. But what we do for sure is we try to, and just as I mentioned, engage the child in the process as much as possible. Here we have child life specialists who work both with siblings and with the children themselves. These are basically developmental therapists who help through teaching and art therapy and play therapy and through a wide variety of approaches to make sure that these children are engaged and involved. And then, in the context of truth telling, if there's a request to lie to a family, we certainly don't lie to the children. And families that are lying to their children, we encourage them not to do the same. And sometimes we ask them a very simple question, which is just, you know, when you were raising them, did you raise them to understand lying as wrong? And sometimes simply talking through the data, talking through our experiences can help families begin to engage their child in their own way. But we have to do this very slowly. It's a dance, right? One of the best ways to get fired from a situation, get removed from a situation is to tell a parent how to parent. And we need to make sure that we are growing in our relationship with them so they can trust us, so that we can help them kind of move towards what we have seen as more effective approaches towards parenting and towards involving their child. And when we think about, it's really interesting that you even put the phrase lower dose in there. When I think about palliative care integration, I actually think of the term titration. And Dr Levine spoke of how we do an introductory visit, which is kind of a smaller dose, let's say, of palliative care at the beginning of bone marrow transplant. And then as needs arise, we come in with a little bit stronger dose of palliative care. But I think you're probably likely asking about things like families that are resistant to opioids or families that are resistant to pharmacologic agents. With them as well, we try to partner and work on these and we try to anticipate these issues. We try to deal with the known opiophobia that many families have, and we try to address it in advance so that if we can begin to sense their hesitancy, we're not coming to a point when a child is screaming or yelling and we're trying to integrate some sort of pharmacologic agent, and the family says, "No. We cannot do that." We are hopefully able to anticipate some of those needs, much like I talked about in my talk. So, Mark, thank you so much for your question. And the answer to the very first part, which is do we adapt our procedures? Absolutely. Every single situation is different. 100% of the cases are individualised. Every family we meet, although we have a standard kind of question approach that we take and we try to make sure we cover those particular questions, every follow-up after that is individualised, every approach we take. Even in the midst of asking those questions is individualised. So, Mark, thank you so much. I'm also recognising that we are out of time, so I do just want to say thank you so much, Dr Levine, for guiding us as a discussant of this topic. I want to encourage all of you in the context of palliative care to compassionately get out there and stomp out suffering. You can be the difference in the quality of life of your patients and families today. Thank you so much and have a great day.