

2025 Sept 24 – CHAMP Advisory Group Call Transcript

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Toni Ann Marchione: I want to welcome Jessica Pope to today's call. She is going to give us a little bit of, a bird's eye view into her world of pediatric hospice and palliative care. I have found that I have learned so much from her, and really how she uses concurrent care to service, pediatric cases for hospice and palliative care. And Jessica, if you could just give us a little bit of a background, and then if you'd like to go, and I'm going to hand it over to Dr. Moss for the rest of this meeting. I just wanted to be able to say hi, and, thank you, Jessica.

Jessica Pope: Hi, everybody. Dr. Moss, did you have anything else that you wanted to introduce?

Kerry Moss: I know I think that that's great if we just start with you. We just welcome to the meeting, everyone, we're glad to see you here.

Jessica Pope: Absolutely. Well, I know that Peter did send out the agenda, and then I also included just a very brief handout there for more of a point of reference. I am hopeful that today can also be an opportunity for us to be able to have just dialogue, answer questions that anyone may have. There is very much an approach with pediatric hospice and palliative care that, I think is independent of everything else legislatively that is going on, and really that approach is based on patients and families. As they're navigating a very scary point in their life, whether this is something acutely, or that's been going on in this moment, and in this situation, or something they've been navigating for years. And so, this is really meant to be more of an overview of how, I typically will approach these conversations with families, but also really looking at our relationship with providers and partners in the community, with our hospital partners, in... in helping navigate some of those conversations. And also bringing to light a little bit more about, how we can best support these families based on where they're at in their journey. So I am, by trade, a child life specialist and a board-certified music therapist. I have been doing pediatric hospice for, going on 14 years now. Definitely always been a passion of mine to work in pediatric hospice, which I know is not the norm, but it really did capture my heart knowing that in what I tell families and I tell providers is that whether we acknowledge that children are facing terminal illnesses or not, it doesn't change the fact that they are. And those that are willing and able to step up and make that experience as good as possible are the people that are furthering this mission. And so, in my...experience in, obtaining additional certifications specific in pediatrics, such as the NICU music therapy, certification and in hospice and palliative care. I was offered the opportunity to sit with our, Pediatric Advisory Council through NHPCO, what was formerly known as NHPCO. And really was able to get an opportunity to work on the ground floor of building up all of these resources related to pediatric concurrent care. Especially knowing that it... even now, here we are, several years later, and there's so many questions that come up about concurrent care. Even 10 years ago, when we were really trying to get those resources out, there were a lot of questions, and so I was grateful for that opportunity to work at creating a lot of those resources that we still use today, and really find myself being, at least well-versed in concurrent care, as well-versed as you can possibly be amidst all the changes that happen just year after year. I still currently sit on the e-Journal Committee through the Alliance for Care at Home, and we're always looking for those contributors for various topics related to pediatric palliative care and hospice, but again, coming from that place of really wanting to recognize that it's important for us as Clinicians, as administrators, as physicians, providers, that we know as much as we possibly can to help with navigating those conversations. So again, my goal here really is just to open up the dialogue, be able to answer questions anyone might have. It's to the best of my knowledge and best of my ability. If you did look through the brief handout that I put together *[copies of slides at end of this document]*, you'll see that there is a slide specific saying, not sure if concurrent care is really confusing or the best thing ever. And that is very much the experience I think most people have with concurrent care the beauty of accessing concurrent care through the Affordable Care Act opened up so many doors for families. But there wasn't a lot of direction on how to enforce or open those doors. So it's like we were given the door, but no handle. And so, over the last...decade, really, we've been working to try to have more of a streamlined approach to how we can introduce concurrent care, how we can bill for concurrent care, and now that we even see more Medicaid changes coming through the pipeline, how we can help advocate for concurrent care in the future. So, for those that aren't familiar. The concurrent care is a door that is open to families that are seeking life-prolonging or aggressive treatment, but may be in a situation where the treatment is seen as futile, or there's unknowns

surrounding the treatment, and if it will be successful. Or perhaps they are just at high risk for decompensation. And what this did is this said to these families of pediatric patients that you don't have to give up. You don't have to stop seeing your provider. You don't have to stop having your private duty nursing in place. You don't have to stop chemo. We recognize that you need a hospice team. You need that high level of care in the community to help you walk this path. And we're willing to essentially foot the bill to make that happen for you, because we recognize that parents aren't going to easily say, no more. So, this really beautiful act that came about allowed them there to be more of a partnership between the medical staff, the families, and honestly, the insurance companies as well, and allow them to walk this journey that ebbs and flows, that has very high highs, very low lows. With the support of something consistent in the home. And we know that kids and really anyone of any age. You go into the hospital when you're having an acute event, you are surrounded by support, you have nursing staff that's checking on you, whether you like it or not, every couple of hours, or 15 minutes. You have physicians that are able to provide fairly quick feedback in the moment. You're certainly surrounded by life-saving options in the moment as well. If you were to go into sudden cardiac arrest and you're already in the hospital, your chances are much higher than if you're anywhere else and you have access to expressive art therapies, right? You have access to child life, you have access to potentially seeing a psychiatrist inpatient, music therapy, all of these different modalities. And then you go home. And when you go home, all of those things go away. And for these medically complex children that have a high risk of decompensation, that have, maybe treatments that are very hard on their body, they are going home trying to navigate all of these different things, which means parents are now in charge of their medical care. Mom just went from mom to nurse. And it's very difficult, and I'm sure there are people on this call that have that experience. It's very difficult to navigate that complete change in identity. And so, again, concurrent care allows this door to be open so that a team can come in and help relieve some of that stress and some of that pressure, and hopefully provide some continuity of care at home when we think about hospice, we think about the 'H' word. It's... it can be a very triggering word for most people. Most people do have an experience with hospice. Not necessarily all positive, not necessarily all negative, right? But they may have a preconceived notion of what hospice is. They might have had that negative experience that's certainly colored their view on what may happen to their loved one or to their child. And this can create an instant barrier when trying to support a family that is eligible for concurrent care. And so concurrent care not only opened up the door to say, if you're 21 or younger, you may receive these life-prolonging interventions while still having access to a hospice team. It also opened up the door for us to be able to alter our language, while still being very truthful and very upfront about the services that we offer. So typically, my approach with families is very clear to say that I know the H word is scary, and that that is who we are and what we do, but let me talk to you about what concurrent care is. Let's talk about what access you have through your insurance benefits. And we can certainly call it concurrent care from here on out. We don't have to use the H word if you don't want to use the H word. That is the services that we're offering, that's still the scope of what we're able to offer in the home, but your access to concurrent care is really what we're trying to explore here. When we typically approach families, it's really hearing their story, hearing what's led them to this point, whether it's a long, complex illness that they've been navigating for 14 years that has finally started to change a little bit, and they're noticing some changes. It could be an acute event that has led to a drastic change in their day-to-day, or it could be a new diagnosis where there's a lot of unknowns. It's really about hearing their story and what their understanding is at that point. And then typically what we do is we assess their access to concurrent care, recognizing that although the Affordable Care Act is acknowledged and honored through TRICARE and Medicaid, if they have a commercial policy, we want to also make sure that we are clear on what that coverage is before we're necessarily opening up the door to talk about concurrent care. The last thing we would want to do is offer something that, unfortunately, the insurance is not quite on board with. I will say, in my experience, that the benefits of concurrent care financially for insurance companies it far outweighs the per diem rate that they're paying out, and so I have yet to come across a commercial policy that set absolutely zero coverage for concurrent care. Typically, we will see about an 80% coinsurance. We will see 100 often. But there's always majority coverage of that concurrent care, and then organizationally, it just depends on how the offsetting cost, is appropriated. Whether it is through charity care funding, foundational funding, or if it is a situation where the family is billed

for that out-of-pocket expense. But it still opens the door for that concurrent care for them to have that team. And then we really identify those partnerships that are important to the family. Concurrent care is what helps create complete continuity and increased collaboration. So by having the hospice team involved and helping with care management in the home, we're able to better connect with the DNA providers, the medication providers, we're able to connect with the hospital, as well, to help provide updates. Our approach that we take here is really connecting with our pediatric palliative care teams at the hospitals, and being able to collaborate and offer updates when we see that a new patient has been hospitalized. Or if they have a patient that they want to bring home, helping coordinate, even going in inpatient to meet with them to start having those conversations again, helping that continuity so that they don't have to retell their story every time they're getting admitted, or every time they're getting discharged. We also work very closely with insurance companies and case managers participating in those monthly or quarterly calls to update on their status. Again, recognizing that there's a cost benefit that comes with having a hospice team involved. We see decreased hospitalizations, we see decreased medication waste, decreased medication usage. Perhaps we've been able to find a more affordable option on our formulary that's offset this extremely expensive prescription that's being sent directly to the pharmacy to run through insurance. And so we can have those conversations and be very open about that. And then we also look at different models of care that are available as well. Concurrent care can certainly be that initial option for families, especially for those that are unquestionably eligible for hospice, but it may not be the most palatable at that moment for the family. If there's access to a palliative care team, it can very much be a conversion model that's stepping into concurrent care, stepping into hospice, allowing there to be a foundation built with the team, or with the organization, or through that partnership before it's introduced. But again, a lot of success is also had just in really Leaning into that concurrent care model, recognizing you're getting hospice level of support without having to give anything up. And then also just making sure that we are addressing needs as they come up, maintaining those boundaries of what hospice is, and how hospice is comfort-directed and comfort-focused. But also using that expertise to hopefully keep that child home as much as possible, and prevent any of those extra things that may come up. Having the ability to call a triage line, because it seems like they may be exhibiting some respiratory distress, and having somebody come out and say, you know, I think maybe this could be the flu, for example, or this could be, some other kind of viral infection. Here are your options. Here's what we can do to help manage you here at home, and if you're really concerned, then we can support you going to the hospital. It's really your choice. But giving them that second pair of eyes, so that the parents don't have to always be the ones making those decisions and taking the onus on what that looks like. But it also means that there's also the opportunity to have a little bit of advocacy, when a family does go into the hospital knowing that somebody has laid eyes on them, or at least talked to them, and given them that recommendation, so that they can then advocate for themselves in the hospital as well. This full model is really meant to be as I said, centered on the journey of this family. I... I know that the... not buzzword, but we talk about patient family-centered care, right? And the humanistic side of medicine. And I think that those are very important phrases to use, it's certainly an important model of care to use. But typically, when I'm talking with families, or I am talking with other providers are doing education, I will actually present more on the idea of a journey-centered care model, where we're honoring the journey that the family is on, and recognizing that there will be ups and downs, and that we have to tailor our approach to where they're at in that journey. We certainly have children on service that are full code. That will never change. That is where they're at, and that's okay. How can we meet the goals that you have, and honor what your wishes are, but also provide you the education? That's the beauty of concurrent care. You don't have to give up any of those wishes, those hopes, those dreams. But you do have people you can turn to when you inevitably do have a question. And it can be in your own space, in your own time. But also looking on the other side of that journey for when they are planning for end of life being able to walk that side of the journey with them as well, and make it look how they want it to look, and advocate for that to happen as well, and really moving into the bereavement space to continue that support. So it really is meant to ebb and flow alongside with the family. Not having an agenda, and again, allows the hospital, as well, to be able to follow the journey as needed with partners in care, and knowing that they have people in the community and in the home that can hopefully help reflect things that are discussed inpatient, or try different opportunities to maybe reach a specific

goal, or try a different intervention. That partnership there is really what's crucial, and I think it's what makes concurrent care as successful as what it typically is for a lot of organizations. That was a lot of information. I did try to keep it as short and sweet as possible. We could talk about any one of those individual topics, probably for an hour by itself, but I did want to make sure the majority today was just an opportunity to discuss and ask any questions that maybe come to mind when thinking about the utilization of concurrent care with a hospice model or with a shared model.

Kerry Moss: I see Barbara's hand is up.

Barbara Cass: Thank you, Dr. Moss. Thank you, Jessica. This was really, really good, and very, very helpful. So I just have a few questions. In your handout on page 3, the meme, I think we could put many, many, many faces and I don't know if that's Bart Simpson, because I don't... I'm not good with cartoons, but many faces in there regarding how to differentiate between concurrent care and hospice care. So this... and I live this world a lot, but this was very helpful for me for the context. And in alignment with that comment. Is there a gap or a barrier that we need to talk about or address to help others understand the alignment with concurrent and hospice care, and also where there may be some disconnects. And my Part 2 question is, as we start at DPH to look at our hospice and our home health care regulations and separating them. Is there a place, and I put this out to the group, where we can be... and again, we do try to be helpful when we develop regulations. Sometimes it doesn't always seem that way, but is there a place where we can be helpful or supportive as we contemplate rewriting these regulations. Thank you.

Jessica Pope: Absolutely. I... I love both of those, or really all three statements and questions. I think that truly the biggest... I wouldn't say barrier, but I think the biggest obstacle when we really talk about the utilization of concurrent care with pediatrics comes down many times, oftentimes, into the delineation of services, and really identifying what the scope is of the hospice team and the hospice provider versus what would be considered part of concurrent care. What would we then shift into insurance to be managing and approving individually? And typically, that has been done, you know, state by state, really talking with the Medicaid office, coming forward with an MOU to outline what those responsibilities are and how we delineate. And I think that it really does come down to identifying those needs. So, for example, recognizing that if a child is trach vent dependent a trach an event, or event, really, is...pretty clearly a concurrent option for care, right? That is life prolonging. If we were to take that vent away, then they would more than likely not live for very long. And so, it would not make sense for the hospice to be managing that as a part of the plan of care. That wouldn't be a piece of equipment that we would be, creating a contract with a DME company for. We would typically encourage that they maintain whatever is already in place from a respiratory standpoint. They're still being seen by pulmonology, they're still going through the authorization process. But hospice certainly is going to have eyes on that vent, and can certainly help collaborate with the pulmonologist to provide any feedback on what may be or may not be happening, so that they can make better choices. But that really is staying in the camp of pulmonology. That's that concurrent intervention. When we look at respiratory distress, however we might recognize that that is a part of the physical decline of that kiddo. Perhaps that they've never used oxygen before, maybe they have, like, an osteosarcoma with METs in the lung. Well, we wouldn't refer them out to pulmonology at that point. We recognize that that's disease process, and that's part of that progression, and so hospice would come in and say, that is a symptom that should be managed. Why don't we look into seeing what we can do from an oxygen standpoint to help you feel comfortable? Let's look into medications that would make sense for us to help support that symptom, and then within reason, being able to offer that comfort. And it's hard when you have such individual situations to be able to put something black and white in writing or in a regulation that's delineating those services. Because there may be opportunities for respiratory distress to be managed by pulmonology. So I really think the obstacle from a state perspective in looking at regulations or how we can... how do we make this work is really putting into writing and putting a plan together of how to delineate services between hospice management and concurrent care management. And there are certainly examples DC just released, their stance on concurrent care coverage and what is considered hospice or not, but oftentimes it requires that deeper

relationship with the actual provider, insurance provider, to be able to dialogue about individual situations as they come up, and that inherent trust that hospice isn't diverting coverage of something, and that we are taking on everything that would be comfort-related. I'm hoping that made sense.

Barbara Cass: Thank you so much, Jessica, and thank you for this presentation. It was great. Appreciate it.

Kerry Moss: Does anyone else have questions or thoughts for Jessica? I loved your, statement of the door without the handle. I'm going to have to borrow that, because that's exactly what it feels like sometimes. is right, we know what's up. As a clinician, one of the things that's harder, we sometimes get... and you know, oftentimes when we're trying to do concurrent care, we're getting... we're possibly moving towards an endpoint in an expedient form, right? Because we know sometimes, although hospice could be beneficial long before the day of enrollment, sometimes families get there when they get there, and sometimes we just get the pushback of dual agency issue, and dual agency, and we just, obviously, the whole point of this group is we don't have any funding that allows for any support of that, so from a state standpoint, so we end up with the dual agency issue, and they have to choose one over the other. And one of the big challenges is when you go back to the patient that's, trait invented, you know, in our system here, we have stringent rules of who has to be in the home with that patient, right? You have to have two trained caregivers. It's very, very different in different states, different hospitals. But two trained caregivers then has to have nursing when available, but oftentimes we have been met with the challenges of when a nursing agency is in the home, that it's hard to bring in a second agency to provide hospice and or palliative care to that family, and that's I probably... I think that would be the biggest thing that clinicians would like to ask of you, is how do we... how do we deal with that? Because what it boils down to for us sometimes, and this is where my heart bursts, is you have a patient that's been on a ventilator for 5 to 10 years, and they've had this same nursing group, and they love their nurses. And then you come in and say, I'd really love to bring the people that will have expertise for the next step and support you. But we'll have to let go of those nurses you know, and I just can't do that, right? Like, ultimately, then we have to find another way around, because you really just take away the nurses that know them and love them is a huge part of how that grief... like, that's how their grief is going to be supported, and so I don't know from a... what advice you would give to clinicians, who I know I'm one of the few on the call that are doing this every day, but what advice you would give to clinicians that really struggle with that piece of dual agency in the home?

Jessica Pope: Yeah, you know, I have to be honest, that's not something that we typically struggle with because of concurrent care. We very much view that home health or private duty nursing as part of the concurrent care interventions, and we encourage them to continue to bill insurance for those hours, and we have had individual conversations with our state Medicaid offices, which I think helps, but really encouraging that aspect of their care to not change, and to see this as an added-on support. We certainly aren't going in and replicating what the private duty nurse is doing, because we don't touch the vent. We aren't doing anything with the vent. We're simply looking and providing that whole, person assessment when the nurse is coming in, or we're offering that psychosocial support. So we're going after the same goal. When we look at things like diagnosis codes, this actually just came up recently with a patient, we... now, every state, every hospice is different, but when we are billing to insurance for hospice for a pediatric patient, we aren't saying, well, we're billing this ICD code. Specifically, we're billing for hospice, and it encompasses that ICD code, but it's not necessarily dependent or tied to that, which is also why we can keep patients on service when they're in the hospital, which was also an agreement made in some of those MOU'd conversations. I think it really comes down to that agreement between agency, insurance, and organization from a hospice standpoint, that we really are leaving everything untouched. That nothing should change, so that you don't have that disruption of who they consider care team or who they consider family. And I think that that's an important aspect to try to integrate into any regulation or any kind of advocacy that we're doing at the state level, because it does make quite a bit of difference in their care. But again, it's not a duplication, because we're really assessing two completely different aspects of the care of that child.

Kerry Moss: And we snap. Go ahead.

Jessica Pope: We've also done a lot of education with our agencies. I mean, typically, you will have a cluster that you use, especially in pediatrics. There are not 900 different agencies in a state for peds. It's usually 3, that are willing to take on pediatrics, and so we've done a lot of education to help educate not only on concurrent care and hospice, but also what do our assessments look like? So that way, their nurses aren't also feeling that there's another supervisor that's looking at them or looking at their practice. We really try to educate them on why we're there. We also recognize that the private jee nurses that have been there for 10 years become part of the family. And we very much treat them as such. We... if the family is open to having that PDN as part of conversation, we want to have a conversation and make sure that they're educated on the care that we're providing, that their questions are answered. Because it's often that private duty nurse that might be in the home that's providing their thoughts on an issue or their recommendations, not in a clinical way, but just being kind of forced into a conversation, and suddenly they are sharing that they might be hesitant about that care plan, or that intervention, or whatever they're going through. So we're also just realistic about that as well, and so we provide a lot of education to the nursing agencies to help with making sure they feel comfortable with our care as well.

Kerry Moss: It's an interesting point. We do quite a... I've done quite a bit of hospice education, trying to help nurses within adult hospice realms feel comfortable with pediatrics. We have not traditionally educated our, our home nursing groups that are doing you know, Schiffner. So we always talk about shift versus skilled shift, right? And that's how we try to approach the billing, oftentimes, is one is shift presence in the home, and one is skilled, bringing the skill of hospice to the home. We've definitely had some, and I know Ross is on this call, we've had some challenges over the years, having that work smoothly, so I think that that's something our state... that, again, here we are on a state group, trying to make things better. I think that's one of the opportunities, is to really fix that piece, because it has been a huge obstruction test providing hospice care and not having children, I really like the point of trying not to discontinue the hospice service on admission, because that becomes a cumbersome paperwork issue for agencies, to be, right, when they come in and we discontinue and they have to reinitiate. That's a lot on the agency. It's equally a lot on the family, because you're really going through a lot of the same questions over again, and so that burden of discontinuation and reinitiation is something that would be really lovely to avoid for these kiddos. So that's another great thinking point to work towards.

Jessica Pope: Absolutely. Especially in the case of those kids, which is almost all of them, that need to go in for a 48-hour rule out, or they're going to the ED because they have some kind of benign symptom, but because... Or they have a complex genetic, illness, and they have to be admitted, and so oftentimes, we will see a pretty quick turnaround, and it's very disruptive to have to disenroll, and then re-enroll, and have that whole conversation again, where we think about regulation, and if we want to mirror the regulations that are in adult hospice, and we look at that 15-day visit requirement. If they're only going to be in the hospital for 3 days and we're able to do a nursing visit, let's say, 3 days before they went in, and then the day that they get home, or the day after, we're well within that 15-day requirement. And we're also showing that ongoing collaboration that we're taking as an approach from the hospice team with the hospital team as well to coordinate that care. And it's a lot easier to coordinate care and make sure that we're getting any DME they might need, any medication changes they might need, if they remain on service versus having to discontinue, reinitiate a referral so we can have access to records, reinitiate conversations about who we are. It's just much easier. Now, if they're in there for an extended period of time, which also happens. I think it's very reasonable if we get to that 14 or 15-day mark and they aren't home, to discontinue hospice services until we have a clear plan for discharge. But that's a much easier conversation to have at that point, and a much easier process to have at that point, than it is for that repeat emergency room goer that wants to present to the emergency room at every cough, or at every concern, because it's typically out of anxiety that we see that. Or it's just a complex kid that has a lot of medical needs and is going to go to the hospital repeatedly until they get to the point where the hospital is no longer their preferred method. And we want to be able to walk that with them and walk that journey with them.

Kerry Moss: Right, but that's that category of patients we often talk about, are the stair steppers, right? They... they come to a new baseline at the top of the... what is their new top stair, and the families don't always recognize

it, so they seek care. When... when you recognize the decline, they don't always, because they live with it, and so sometimes those families do need to go back to the hospital for... for quick check-ins, 24 hours, emergency room visits, and it's... we want to be able to support that, right? That's why... because again, we want to be able to support what their journey is, that's so important.

Jessica Pope: I also want to support them. As well, we want to support the team inpatient, and be able to offer information about what might be going on at home, or conversations that are going on at home. If a family is being presented with the opportunity to pursue a trach. For example, it could be an attending that hasn't actually rounded on this patient before in the PICU, and maybe not familiar with conversations that have happened. Having the inclusion of the hospice team that maybe has been very slowly, but very surely navigated some of those goals of care conversations, might just be able to offer some extra support. And not just with the family, but also with the attending, with the team that's inpatient, so that they can feel that they are providing the best options possible for this family, and then hopefully we can honor what their wishes are. And so it... there's really a lot of benefit to being able to remain engaged when hospitalized, for sure, and I think there's still ways to satisfy the regulations that are already in place from, like, even just a CMS standpoint. With maintaining that, but that is very much a state-based discussion. I've monopolized your time. I want to let Melissa speak.

Melissa Witthoft: Sorry, thank you. I just had a question, Jessica. You talked about the education that you were doing, and I would imagine that there's a level of complexity to that. Can you talk about the different audiences and maybe some of the steps you've gone through just to make sure that what you're doing is comprehensive and you have everybody, kind of as part of the same, thought process?

Jessica Pope: Yeah, absolutely. I think that the key players in that patient's care are really the first people that need the education. So typically, yes, the private duty or home health nurses that are in the home know this patient every day, but we also want to provide education to the DME providers so that they're aware, if they get for example, anybody that is on an event. It could be the referral can come from anywhere, right? So, it could be a trigger point for them as a D&E company to say, hey, this kid, you know, has been on our... on our list for about 10 years, and they have this, huh, they have this illness that doesn't have the longest prognosis. I wonder... I wonder if this could be a potential family that could benefit from services that we use. But also even from a billing perspective, we don't want hiccups with any of our patient families, when it comes to getting care, and so if we can kind of cut off those questions at the head, that'll prevent there being any kind of disruption in service. The last thing we want is for a family to get a bill or to get a call from a company, a DME company or whatnot, and hear, you know, we can no longer service this vent for you. We will need to switch it out or discontinue it. That is a terrifying place for a family to be in. So if we can provide the education to the DME company, that call won't be made, because they will hopefully understand the limits in the realm of how concurrent care operates. And there's also, of course, the education that can be done with, our hospital partners, whether it be with the, PICU, typically, because we do obviously take care of many of the kids that end up in the PICU, or the intensive cardiac unit as well, but also looking at case managers that are doing discharge planning. They are the ones that are typically trying to congregate all of the orders and all of the plans for what we're doing when we go home. If they don't have a solid understanding of what concurrent care is, they could send the wrong order to the wrong place, or they could inadvertently cause another one of those hiccups when it comes to discharge, because maybe they contacted a company and wanted to start a new med, but that med is aware of what hospice is and says, no, we won't cover it. So it's important for them to also be on the same page of what concurrent care is. I've also really devoted a lot of energy and a lot of time in working with specialty clinics. Especially those that are surrounding the more complex patients that we see. So, recognizing that our genetics teams that are associated with the hospital systems, they... they may want to know that there is a resource, should they get a child that's referred to them with a genetic illness of some sort. We work... I work very closely with the perinatal teams to identify any of those potential needs after birth, just providing the education to the family ahead of time so that they're not faced in postpartum with also making decisions about where they're going to go and how they're going to get there. So knowing that if we have a referral prenatally for a T18 baby, a trisomy 18 baby that baby

may not make it out of the hospital, but there is very much a potential that that baby could come home and could live a year or two years. So, we want to make sure that they know what resources they have available, not just the family, but also the perinatal team and the MFMs, the OBs, etc. And then, also, I think just general education is so important to do, with any of our kiddos that are on service. We do try to reach out to the schools to offer insight and support to the schools, so they know how to address things as they come up, or just have more tools in their own tool belt of how to support the family. So whether that be how to support a sibling of a child that's navigating a life-limiting illness, we want to be able to provide that support. Also, bereavement. And knowing that it might be really hard on a sibling, to have to draw a family tree after their sibling dies. And...how to navigate those conversations and questions, because they may not have access to a guidance counselor in that moment, or there might be questions that come up that we just want them to have the tools to be able to feel prepared for that. So you can see, like, this education can continue and continue and continue. And then the last one I will say is just the, again, the insurance side is really educating those case managers that are maybe working with an MCO, that may be, spearheading, you know, we have all these new programs that are coming out for better health and betterment in a medical journey, and so if there is a medical case manager with their insurance company, let's also instruct them and provide some education on what concurrent care is. And open up a dialogue, so if there's ever a question about coverage, or a new service, or anything like that, we already have that direct line of communication to be able to offer any kind of insight or redirection. And hopefully, we would also be able to get a heads up if there were any issues or concerns regarding that patient's care, we would find out before we receive a denial letter in the mail.

Melissa Witthoft: And Jessica, I don't assume you have all these conversations yourself, otherwise you wouldn't be sleeping.

Jessica Pope: I do.

Melissa Witthoft: But, what's the scope or the tier of people who would be delivering some of these conversations? Do you have dedicated team members, just from a capacity standpoint?

Jessica Pope: I will say that, [I conduct] the majority of the education and conversations, if I'm being transparent, but I do think that there is that onus as well on the collaboration that can happen with the entire team. So having that nurse case manager be able to also have a direct line of communication with the insurance case manager is vital. They're able to provide them updated clinical information in the moment if it's needed, and be able to help clarify any of those needs that come up. And the team also...we encourage them to have that direct line of communication with our attending medical director, the AMD that they've elected for the community. We also want to make sure that they're connected with any of those subspecialties that are crucial in their care. So that way, if we are seeing something in the home, even if we're not managing it let me call the cardiologist and give them a heads up. Let me... let me go ahead and coordinate, because they're out of these supplies...let me coordinate with the GI clinic and make sure that the GI clinic knows that they are out of formula and they're out of, you know, Mickey buttons. It's not that we're taking over the management ordering those things, but it does open that door to be able to communicate and educate in the moment as well, about what and how we delineate care from a hospice perspective, and then hopefully that's breaking down barriers as well about what the H word is, and can help foster some of those relationships. So we do encourage all of that active collaboration as well. And then I think just as an organization, there's always an opportunity through marketing or through other opportunities to always provide education, and have people kind of at the ready to be able to at least offer the basic information surrounding concurrent care for pediatrics. So that way, if they are ever in a conversation, perhaps a liaison at the hospital gets roped into a pediatric case. They at least have something in their arsenal that they can be able to start conversations, and then they can certainly pivot over to someone that has more extensive knowledge and that can dive deeper if needed.

Melissa Witthoft: Okay, thank you.

Kerry Moss: So, I just was going to ask one last question, and I have... I will have to leave at 2 as well today, so I don't know, we may wrap up by then, but my question to you is really in that beautiful model that you suggested, that I love, the picture, in... that really shows us the distinctions of what used to be, right, curative, and then it was palliative, right? And there were two doors. And now we have that beautiful, picture graph that shows us, even survivorships included on that, that now, that diagram. My question for you is - Do we view...in your viewpoint, is concurrent care and hospice care, really, when we think about pediatric palliative care for patients, is there a role or a distinction for a palliative care support service in the home versus a concurrent care-based hospice care support service at the home?

Jessica Pope: Yes, and this is really the other topic that we could easily spend another hour on, and that is pediatric hospice eligibility criteria. Right? There are many ways to approach this. This is another no doorknob was provided, when concurrent care was rolled out. There are certainly, recommendations that have been made, and there are several resources that are out there to help with navigating this. But as a physician. It's already difficult in the adult world, being able to offer prognostication, and in a child, that becomes infinitely harder, because they are the most resilient little beings in the entire world. You can have a child that is playing and active and smiling. And then they die overnight and in their sleep, or where they don't wake up from their nap. Conversely, you can have a child that is on an Epidrip in the hospital and just had 2 cardiac arrests, and, you know, they anticipate as soon as they bring him home and remove the epi-drip that he will fade away, and then he lives for 4 weeks. There really is not a good, in my opinion, at least in my experience, there hasn't really ever been a clear model that shows us, there's no fast score that we can really go to help us with prognostication with kids, other than those that are very clearly at their end of life. So, typically, I think what we look for, if we just break it down into a non-hour-long discussion, is really looking at the parameters that we view concurrent care affecting their longevity. And that's really where I think we can distinguish between palliative and hospice. If a child has a life-limiting illness, that could mean anything from 6 months to 22 years. So where in that spectrum do we involve hospice versus palliative? And I think it really comes down to the medical complexity and what comorbidities are we seeing, the risk of decompensation, and especially from something like a respiratory illness or, a potential change in their mental status. And then also just disease progression and prognosis in general. For example, DIPG, we know that upon diagnosis, that that is a terminal. I know we have the one case that was just recently released, but that is a terminal prognosis. And so, at time of diagnosis, DIPG, even with chemo, or with radiation, or with Avastin, or whatever. That is typically going to be hospice-appropriate from the start, because we know that there is no cure, we know that eventually, and it could be anywhere between 6 months to a year, that they... they will die. And so, those three are really the pillars for eligibility that we look at. So, diagnosis can usually be pretty easily, to assess, especially as a provider, looking at that whole picture. But when we look at things like medical complexity, a child that has CP, is not necessarily going to immediately be hospice appropriate by diagnosis, right? Cerebral palsy can certainly have a spectrum of how it affects a child. It can be anywhere from, like, a spastic CP to severe spastic CP with all kinds of other comorbidities, and it's really looking at that whole picture. If we saw a child that had CP that, certainly had some spasticity, maybe had some seizures, I would see that as palliative, especially if they have a lot of hospitalizations. Because there's certainly medical complexity there, and they will likely need some help with navigating goals of care conversations. There's going to maybe be med changes or surgeries in the future. But if that CP was also, let's say, comorbid with a severe HIE, or let's say that there was CP, but there were also some congenital heart defects, or anything like that, we start raising that acuity into more of a hospice realm, because we know that if one of those systems breaks down because of the common cold, that everything will follow suit, and could follow suit very easily. And then I think that leads into the third pillar of that medical fragility. Recognizing that the hospice diagnosis alone might not paint the picture, but they've been in the hospital 7 times in the last 2 months, so clearly there's a lot going on there. Perhaps they're ready to have goals of care conversations, and they want to talk about where that line is that they would like to draw in the sand. They maybe are not at the point of getting a trach, and they're at the point now they want to talk about what that would mean if they were going to get a trach. I see that as being very much in line with, like, a hospice philosophy of, are we really choosing comfort here, and really going for a comfort-focused model of care for quality of life? Or are we going to pursue the trach and all aggressive interventions, and will

that trach significantly improve their longevity? And then that's where I think we look more at the palliative - very much like delineation, not black and white - right? So I think that it's, again, very much of discussion, but I think those are the three pillars that we really look at. And then that interchangeable support with palliative care, if it is available, is just being able to help meet them where they're at, and then convert when the timing is appropriate into a hospice model of care. Does that answer what you were trying to ask?

Kerry Moss: It does, and I think it was a planted question a little bit, because I think one of the hardest pieces is that question of eligibility, and it's hard because what I'm learning in my ages of doing this is, like, the product of hospice is really a gift to anyone at any stage illness, right? The concept of choosing quality and the concept of life, and it's hard because a trait conversation can happen 10 years before the death, but does feel like a hospice conversation, does feel like a really sentimental goal of care conversation. And so, it's a challenge because I really wish all children could benefit from the concept of hospice and concurrent care without a 6-month death prognostication really being a driver. And that... that's a bigger global... that is not for this task force. Let me... let me fully admit that is something we as a state are going to solve, but it's an interesting thing. It's an interesting concept. So, no, I appreciate your thought... your thought process, and I appreciate that it is sometimes challenging for these patients and families, and if one system does go, they may leave us, or they may be here for another 10 years, and so how do we best meet their needs? Yeah. And of course, in listening to you speak, I think everyone on this call would resoundingly say it'd be nice to have someone with your advocacy involved in every single child's case that has medical complexity, right? Because we suffer with the lack of medical homes. By virtue of so many specialists and so many pieces, and hospice, and the philosophy of hospice, more than end-of-life care sometimes, provides medical home in the much-needed populations, and so...

Jessica Pope: Absolutely. It's just more of a thought, but it definitely answers it. Okay, good.

Kerry Moss: Thank you for that.

Jessica Pope: To add on to that, just, to also I think an important part of this, too, is when we look at the regulation, that 6-month or less prognosis. With concurrent care, that's inherently kind of the blown out the window a little bit. And the approach that I've historically seen taken that I think makes a lot of sense is that idea that if we were to remove all of these life-prolonging interventions, is there a likelihood that there could be an event leading to death within the next 6 months? So when we think of a vent, like, if we remove the vent, that there's a pretty good indication there that there would be a shortened prognosis. If, a typical... like, we've worked with a lot of pre-transplant patients, where they are really not doing well, and they are on the transplant list, we are hoping for the best. Well, in that moment, pre-transplant, they are very much hospice eligible. If we don't get a liver in the next 6 months, we could be looking at an event that would lead to their death, but then they're able to get their transplant. And once they get that transplant. let's, you know, they're in the hospital for a long time, so we're already discharging, but then let's reassess. How are they doing? We look at bone marrow transplants all the time. If they have a failed bone marrow transplant, they're almost always going to be hospice eligible, because what are the chances that's going to happen, right? So I think there's, again, a lot of nuances there. There's a lot more kids out there that would benefit from the services that don't know they have access, or in a lot of areas don't have access, because they're not a pediatric team that's able to service them. And I just want to also, before we end. Speak to the unbelievable, joy that it brings me knowing that this task force exists, and that there is this motion, and this support, and this recognition that children are entire... they deserve, and they're entitled to an end-of-life experience that is going to be what it needs to be, and not forced into something that it doesn't have to be. So thank you all for your kindness, your advocacy, your willingness to be on this task force, and to see the bigger vision here, because it does make a difference, and we have letters and letters and letters to prove that from families. So just thank you, and thank you for all of your great questions.

Kerry Moss: Right, and when we think about what it can do for the children and the families when we de-escalate our medicalization of children's lives, it's a really beautiful... it can be such a beautiful outcome for these... these humans. Just because we can doesn't mean we should, and we talk about that, right? The language of doing

things for, not to. We use that language all the time, and... Trying to decide the next step, singles of care I will be... I'm not sure if others have questions that they would like to address at this point. I know that Tony Ann is not able to be on with us. Melissa is here, but I am, do have a hard stop today at 2 o'clock. Are there other questions that people would like to address? Or questions, more on what we've been doing with the breakout group, or anything else that people would like to address today's meeting.

Melissa Witthoft: Dr. Moss, did you want to run down a couple of bullets that we pulled together, just to let people know what we've been doing in the past?

Kerry Moss: Sure, absolutely. So, I think there's been, very successful meetings with the smaller group that's really just looking at where we are going to move the needle in the time allotment that we have, which, as we know, is just, how is it already October, almost, and how is it almost fall, like... where's the time going? So, some of the bullet points or the areas of identification that we're spending the most time working on is looking at the, really sharing some best practices during these meetings, and so Jessica was our first foray in that, to just bring someone that's doing the work, maybe at a different vantage point, and really understand what they've experienced, but also just, garner from the wisdom they've had in their success in other places and in other ways. And, you know, I talked about it would be interesting to talk to someone emphasize at some point a little bit about something like MOLST, because that is, you know, something that people don't always understand what a MOLST is and what it can do for you, and I know Barbara has spent so much time dedicated to that, so that... you're on the list, Barbara. We're looking at other state models to consider the best practices to help and to reflect, and we're really trying to look at models that have succeeded and models that have had less funding, too, because I think we found some great examples of states with a lot of funding, and then that just leaves me jealous, but, no, it does not. It leaves me inspired that we can do that, too. Extracting and filing data metrics from existing resources, reports, and practitioners. Continuing to build the RN curriculum and codify RN certification and decrease access to skilled pediatric hospice practitioners. To develop and propose baseline recommendations for facilities, programs, licensure and certification, and to pursue methods to inform and educate practitioners and families to offer more comprehensive and more timely support. So those are kind of the areas of focus at this time, and I'm looking forward to the ongoing work. I feel like this concept of the monthly advisory, group meetings, and then the two breakouts. We're meeting twice a month, I really feel like we're going to be able to get some... some good information together by the time we send this all in in February. Anyone have anything to add to that? All right, well, I just want to thank Jessica for coming today and sharing your wisdom. It is, it's just lovely to have... it's like having a cup of tea with an old friend. I feel like we could just talk all day, but we're so glad to have you with us, in this initiative, and we thank all of you for giving us your time today. We hope you have a great afternoon, and I look forward to seeing you next month. Our next meeting, which was listed to you, will be October 29th, from 1 to 2.30 p.m., and so we'll look forward to seeing you guys then.

Jessica Pope: Thank you, Kerry.

Kerry Moss: Thank you.

Jessica Pope – CHAMP Advisory Group Pre-read/Handout



**Jessica (Sturgeon)
Pope**

Experienced Child Life Specialist Board-Certified Music Therapist with specializing certificates in hospice and palliative care and NICU music therapy.

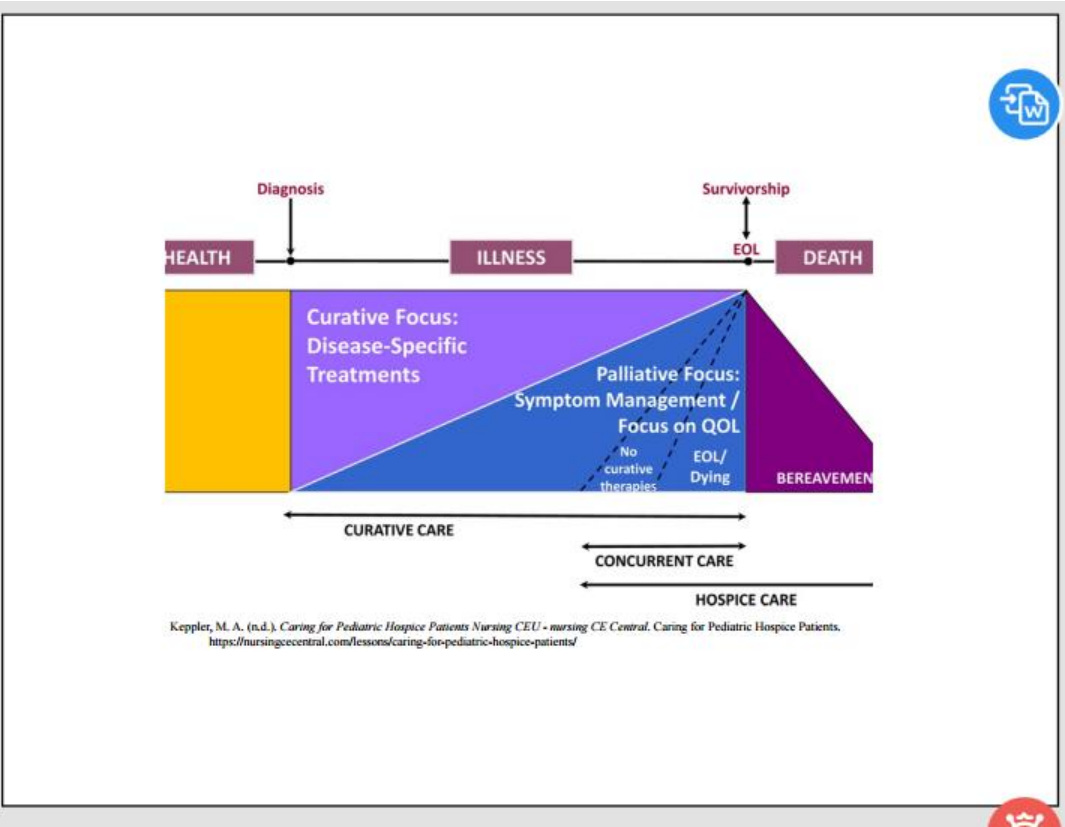
Current Director, Pediatric Care with ADC of ~ 80 pediatric patients under a concurrent model of care. Specialist in program development, management, and coordination for pediatric hospice, palliative, and concurrent care through ACA Section 2302. Previous member of The Pediatric Advisory Council and currently sits on the Pediatric E-Journal committee with The National Alliance for Care at Home (formerly NHPCO).









Concurrent Care

"Concurrent care allows select disease-directed therapies to facilitate transitions to hospice, with the aim of promoting goal-concordant care. In collaboration with specialists, hospices oversee treatment plans, which are adapted to meet patient goals. Concurrent care may act as a bridge for patients and families, allowing them to begin hospice services without fully stopping treatment that they have come to depend on for prolonging life." (JAMA, 2023)



Sustainability

Payors and Partnership

-  Medicaid, Tricare, Kaiser, Private Insurance through established criteria
-  Partnerships with hospitals, private duty agencies, DME companies, insurance case managers, and specialists/PCP
-  Popular models include a conversion-based model vs concurrent care model
-  Mutually beneficial financial benefit through the inclusion of a hospice team in the home in prevention

