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It is my first time being at a conference where patients and families are here. And so I hope that you have feedback for me because I think it's a really exciting time in pediatric and adult medicine. In my past two years here at Michigan I've been invited to give talks at conferences throughout the country, but also internationally, on how we are communicating with pediatric patients and parents and young adults about difficult topics. And so you are my audience, and so please, please, I welcome your feedback.

So to give you some brief background on myself, Dr. Norris shared that I am a pediatric psychologist, but our transplant program here sees patients into their 30s, so I certainly work with young adults. But prior to working primarily in transplant, I worked in pediatric palliative care. And so often my role was working with patients and families and discussing difficult topics such as end of life care, advance care, planning.

And when I made the transition to cardiology, I realized that there were really notable gaps in our understanding of what pediatric and young adult cardiology patients want with regards to having these conversations. And so brought that clinical experience and combined it with my research interest in health care communication to begin to investigate this understudied area.

I have no disclosures, but I'm on Twitter. I would like to have knowledge of these sources of funding for the research that I am doing. We can't do this work without it, so thank you.

So first what is patient and family centered communication? We all hear the buzz term, and the providers in the room likely say we provide it, but it is not as simple as one may think. And so per the Institute of Medicine and other resources, it includes the provider giving quality information in the appropriate quantity with sensitivity to a patient's values, concerns, and feelings, and includes a partnership with the patient and their family on their preferences, goals, and concerns. So this in and of itself is a mouthful to say, and even more challenging to provide.

But we know that it's important and so I would say, even for our surgeons in the room, communicating with your patients and families is the most common procedure that you will do in medicine. You will talk with your families and patients more than any other thing you do.

But if you think back to medical school or nursing school or where I'm where you did your training, you probably didn't have your long didactics on building communication skills, or you might have had one, you know, attending that helps you focus on that, or you may have attended one lecture. And so this is not a focus, but it's important, and it's associated with really notable and desired outcomes.

And so when we look to the communication literature we know that when we are good communicators as providers, our patients are more adherent to their medical regimen, which is absolutely necessary, right? They have better satisfaction. Our diagnostic accuracy is improved. Our patients and families walk away with better understanding of their disease and their treatment options, which allows them to engage in decision making with their medical team more efficiently. It leads to shortened hospital stays and earlier discharges, which is important to our institutions, insurance companies, etc. and reduces medical errors and litigations. So it's important.

But it's not easy, and across the pediatrics and adult literature, across illness groups, we see many communication mishaps, barriers, and challenges. And pediatric oncology is a field where they've done much more of this research. And when you ask a pediatric oncology attendings, you know, who've had many years of practice where they give a lot of difficult news. 50% of oncology attendings say they feel uncomfortable discussing topics such as transitioning to non disease directed treatment with their patients and families. That number is greater for our trainees and our fellows who are in the ICU and at the forefront of having these conversations.

And then when we ask pediatric patients themselves-- so again I'm referring to an oncology population, and that's because this work hasn't been done in pediatric cardiology yet. But when we asked the pediatric oncology and young adult oncology patients, they are pretty dissatisfied with the communication that they are having with their medical providers. They don't feel like they are invited to the table enough. Their parents are really the ones that the conversations are directed at.

And then, lo and behold, when we ask them and their parents, what do you think they would want? So with really important things like where would you want to die, home or hospital setting, parents and pediatric patients in oncology have really discordant ideas. And so there are barriers and it's a challenging thing to do.

So given my role, my clinical work in pediatrics technology, I've started to set out to describe this issue in pediatric and young adult cardiology. And so we have first started to conduct an international survey of multi-disciplinary health care providers on their current practices, beliefs, challenges, barriers, to having these difficult conversations around things such as end of life care, prognosis, retransplantation, completing advanced care documents.

We developed a 107 item Qualtrics survey. It took about 10 to 12 minutes to complete. And then it was sent out through a number of listservs. This included, specific to cardiology, the International Society for Heart and Lung Transplant listserv and the Pediatric Heart Transplant Study listserv.

Data collection is ongoing, but for this talk I wanted to do just some brief look at what we have so far. So far we've had 82 cardiology providers respond. You can see a large portion of which were female and identified as white Caucasian. We do have a good range of years of practice, so about a quarter with five or less years of practice, and about 20% with greater than 20 years of practice. And of our cardiology respondents, they were heavily involved in clinical work. You know, about 70% of their time is in patient care.

And you can see here on this graph, and most of our respondents were attending physicians, or transplant coordinators, nurse practitioners, PAs. And so we asked, how comfortable are you with discussing these difficult topics? And I work in organ failure, so I was specifically interested in discussing the potential need for retransplantation, providing prognostic or survival statistics, discussing things like death and dying with your patients, or engaging your patients in advance care planning.

And I specifically pulled out the data related to talking with young adults so that we can hopefully reach both our pediatric and adult providers in the room. And you can see right down the line there and this Likert scale from not comfortable to very comfortable, our providers are reporting that, you know, I'm not super comfortable with this but I also am not, like, terribly frightened to have these conversations. But there's a lot of discomfort reported, and we're going to look at this further and break this apart by disciplines and years of practice et cetera to hopefully get some more insight into this.

But we know that in addition to discomfort there's a number of other additional barriers. So we've already talked about the lack of communication training in medicine. There are time constraints. It is challenging. And it takes time to have these discussions.

In cardiology, there's often an unknown prognosis. And Terry alluded to this at times when she was given-- you were given statistics, and you beat those statistics. And so cardiologists will say, we don't really know what to tell them, or we hesitate to tell them something wrong. And so I think that that's a huge barrier in cardiology. We often have acute on chronic illness. And so how do we balance that?

Providers report that the family or the patient, they may not be ready. They may not be able, they may not be wanting to hear this information. Cultural and language barriers, of course. And then the difficult balance of hope versus realism. This was one of the first questions in this morning's talk on how do we talk about these neurodevelopmental risks, you know, when there is anxiety and we want our patients to be hopeful. This is a challenge and it's a barrier.

And so not surprisingly, we see gaps across the cardiology literature, and what we are communicating. So this is an adult study done by Wachter and colleagues looking at hospitalized adult patients with heart failure. And you see here that with regards to DNR orders, 5% of the adult heart failure population had DNR orders in the medical chart compared to about 50% of adult lung cancer and adult AIDS patients.

Now you may say, OK, well you just told us prognosis is different, you know, for cancer populations and AIDS populations. But this study also asked providers what do you think the prognosis is of these patients, and there were no statistically significant differences between prognosis. So all of these providers were given these three patient populations similar prognosis, but you can see the imbalance with regards to talking about or documenting a DNR order.

I'm looking specifically at an adult CHD population, things like did we discuss advanced care planning with our medical team? Only 13% reported that they did in a US sample, 1% in a Canadian sample. Actually going to the next step and completing that advance directive, 21%, 5%. And then documenting a durable power of attorney, less than 20% both here in the US and in Canada.

And so again, I was interested in this with regards to heart failure. So we asked our adult cardiology providers, how often do you talk about these things with your young adult patients. Now this age group is 18 to 24, so not their parents, but these patients themselves who are the ones making these decisions, and consenting to things like organ transplant. And things like, how often do you talk about retransplant? Right now, graft survival is 12 to 15 years. In their lifetime they will be facing discussions and conversations around retransplant. And I was surprised to see that we were not having scores in the 4 to 5 always range. How do we have informed consent to move forward with transplant listing if we are not discussing things like retransplant, prognosis, survival, et cetera, with our young adult patients? And then even more so, you know, advanced care planning and things like that are happening less.

So you may say, OK, well, we're not talking about it a lot. There's a lot of barriers, but maybe our patients don't even want to talk about it. And so there is some literature on this. And when you ask adult congenital heart populations, the majority, 80%, say that they do want to talk about these things. And more specifically, that they would like their provider to bring it up. And they suggested, this adult study-- now, this included adults into their 50s-- that the age in which it should be brought up is around 18 years, when healthy, and before being diagnosed or hospitalized with a really serious complication.

Now again, this was a population of 18 on up, suggesting that these conversations should happen at age 18. For those of us that work in pediatrics, and we've already talked about transition, you know, can you imagine that we are now transitioning to their adult provider? Their legs have just been cut off from underneath them, and now this unknown adult provider is the one being asked to have these conversations with them. So this is something we need to be definitely thinking about on the pediatric side as well.

Also, the guidelines state-- and this is based on the little amount of research that has been done-- but adult congenital heart guidelines state that all congenital heart adult patients should be encouraged to complete an advance directive, ideally at a time during which they are not extremely ill or hospitalized.

So we know these topics can be difficult to discuss. And as a result, as providers we may not be discussing these topics as frequently with our patients and their parents, despite their preference potentially to do so and despite guidelines from leading organizations to do so.

So I want to focus the next half of my talk on some tips for how we do this. And I will say that these tips are as much as possible from the literature base. But as I've already alluded to, there is no literature base in pediatric cardiology which we will hope to address, so this is gathered from adult congenital heart disease and also from pediatric oncology.

But we have a study going on here right now. It's a small pilot study, where we are actually interviewing our pediatric patients aging in range from 12 to 24 years of age and their parents, and asking for their insight on how do we have these conversations. When would you want to have them? Who would you want to have them with? What do you understand after walking away? So I hope that in years from now we'll have some better guidelines for US providers and parents because we can appreciate that this is not easy to do. With that, I'll try to provide some tips.

So first of all, I think it's important to consider your population. So I'm focusing in on this young adult group as part of this talk, but this is a group where 18 to 24, 25 years of age, autonomy is important. For our patients with congenital heart disease, they have had a lot of parental and medical monitoring their entire life, and now they are trying to separate from their parents, to establish themselves independently. They often are seeking some control and trying to identify who they are separate from, and also inclusive of, their heart disease. Relationships, peer and romantic, become of increasing importance, and this need for privacy. And so these are things that are important to consider when thinking about how you're going to discuss these more difficult topics.

And then specific to young adults with CHD, research has shown that some adolescents and young adults may present with the misconception that they have been cured, and that the chronicity of their congenital heart disease is not apparent. So that's important for you to know. There is some research to suggest that adults with CHD overestimate their life expectancy.

As we've talked about for a subset of our population, there are developmental, cognitive, executive functioning delays. This can impact decisional capacity as well as what they are able to understand during these often difficult and complex discussions.

And we know that there are high rates of mood and anxiety disorders with unfortunately low rates of mental health treatment. A study by Adrian Kovacs found that 50% of adults with CHD met criteria at some point in their lifetime for a depressed mood or anxiety disorder, and of that group only 40% had actually had mental health treatment. So this is another thing that we need to think about when discussing difficult topics.

Now if you walk away from one thing from my talk it's this. I am not advocating for every single young adult or pediatric patient should be forced to sit down and have a discussion with their provider about death and dying in their end of life care wishes, by no means. We have to assess what their communication preferences are. And as I think my team can attest to, that is one thing I'm a mad advocate for, and I'll give you some examples of that specifically.

So these are two patients that I've seen. A 19-year-old white female, middle class. I'm going to put them both up because I want to highlight some of the similarities. So same age. Both from middle class families, both educated, attending college. Both with highly involved parents. And had been followed for most of their childhood for heart disease, and both presenting for a second transplant. So they've already been through this once. They're familiar with things. They know the health system. They also both present with an anxiety disorder, but when it comes to discussing the tough stuff, they could not have been more different in what their preferences were. Megan, for example, wanted all communication to occur directly through her, would become upset when providers came in the room and started talking about her medical care with her parents present. She also wanted to very thoughtfully complete advance directive. She wanted to think about what she would want if she were unable to make decisions for herself. Who she would want in the room, what she would want as far as a funeral, et cetera.

Now Gabby on the other hand, did not want any of this discussion. She wanted all conversations to happen through her parents. She really relied on her parents to be her primary medical decision makers. And I will tell you that many providers, nurses et cetera, came to me and said, this is wrong. This is uncomfortable. We have a 19-year-old who's not participating in rounds. And I said listen, to provide patient centered care it has to be in line with their preferences. And so please, please know that for some families we need to provide those prognostics survival statistics or engage them in these advanced care discussions based upon what they are ready for and what they're interested in.

So with that, one tool that I developed with a group of patients themselves, actually-- they helped me with every word on this tool. This is our My CHATT tool, communicating health information about me to me tips. This goes through how they would want information shared with them, what types of information they would want discussed, who they would want to give that information, what kinds of media they would like. I give this as part of our pre-transplant evaluations here. And it has helped because, you know, I think we're having these conversations earlier, so if something unexpected or sudden happens we've had this discussion at a time of more stability, as much as possible when we're talking about transplant.

Others have suggested this ask, tell, ask, approach, which I think is also very good. So asking your patients and families, what do you understand, what are their worries, and what would they want to talk about. Tell them what they've asked and then confirm their understanding.

I also have found that it's really important to normalize the discussion, so I talk about this or I bring this up with all of my patients. Some of my patients want to talk about this while others do not. Some of my patients worry about this, I wonder if you worry about this. This is some of the language I recommend.

We want to make sure that our language is simple without medical jargon. Using proportions-- seven out of 10 when giving survival statistics or prognosis as opposed to saying things like 70%. We know that this is better for patients with regards to health literacy. And when asked to provide prognostic information, you know, you can own that we don't know for certain, and it may be this or it may be that. And that's OK, but families need that.

And specific to end of life language, allowing for a natural death or stopping machines that make your heart beat, what I ask you to not do is use words like withdraw care or withdraw support. Because actually even when we've stopped non disease directed treatment, we are still providing support and care to our patients and families. And so when we say things like, would you want to withdraw care for your child, or when would you want to, that can feel very harsh for patients and families.

Honesty and genuineness. It's OK to share your emotions. It makes me sad to share this news with you, that's OK. To be real and raw with them. And this tip, this empathize, but don't take it too far, this comes directly from my work with young adults. I think that as providers we-- especially when you've been working in the field for a long time and you have met many patients and families and walked this course with them, we feel like we understand what they're going through, and we may say things like that like, I understand this is hard for you. And my young adults will say, no, you don't. Right?

And so instead, what we've talked about and I said, you know, I've asked them, well how do we express this, because we do have empathy. We do have sympathy, and we want you to know that. So this is instead a tip or a line. You know, I don't know what it feels like for you, but I do care about how it feels for you. And I think that that shows that we're not saying we know what it's like to be in your shoes, but we have experienced this and we want to know how to best help you.

So I think providers often really try, are well well-intentioned and want to express that empathy and then sometimes our patients and families can get upset by that. So keeping that in mind.

Other tips. You can see if I have a lot. When having a difficult discussion, things like advanced care planning end of life care, it is best, and this comes from the literature, when the provider is someone that they've known. So again, when you're thinking about transitioning our CHD population, it may be best to start these discussions on the pediatric side and help transition it to the adult side, where they've known this provider for all of their life.

We need to make sure that there is enough time for the encounter. Respect their need for privacy. Who do they want there? I appreciate that training is important, but these may not be the best times for our trainees to be present, and we need to think about that and ask our patients and families.

The status and the approachability of the provider. Now, specifically, the research suggests this is a good time to leave your white coat behind and you know, first name basis. I love in our pediatric transplant team when I go in and say, oh, Dr. Schumacher is coming in next and the patients say, you mean Kurt? Yeah, I mean Kurt. You know? And that is important, especially when having these discussions that patients and families can feel like that.

Using open ended questions. For some families, they may want to record the conversation, have visuals, and then, as we've already talked, kind of that asking patients and families what they've heard. So I will often say things like, we've said a lot today. I know I've missed things. You know, what questions do you have, as opposed to, do you have any questions.

All right. And so, thank you and I look forward to any questions or comments afterwards.