(PLEASE NOTE: Transcribed automatically by Vimeo; mistakes are possible/likely. Our apologies.)

TRANSCRIPT - GR 11 08 24 ***"When the Medicine is Not What Makes it Hard: Navigating Ethical Questions in Practice"*** guest speaker Rebecca Volpe, PhD, Penn State College of Medicine

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Internal Medicine Grand Rounds

- So our committee is named for Ann Brody. Her expertise was presentations and achievement and she so valued her longitudinal relationship with her personal position, that she committed her safety the Pba School of Medicine, and to Dr. Corbett, with instructions to ensure that they were physicians in the future who could care for patients as he had cared for her. These, of course, are Brody and Dr. Corbett.
- It's a little tempting to look back at those home visits that happened 35 years ago, and think well, that was a different time, but it was radical at the time, and radical still, this is a doctor, and the patient, recognizing that the health system was not able to deliver, and they were making their way together to find a new way.
- They were also committed to making sure that future generations of doctors could work together with their patients to find a new way.
- Each year the Brady committee invites an external scholar to help us look at ourselves critically.
- Dr. Rebecca Bolte is the 2024 brody medical Education scholar joining us from the Department of Humanities at Penn State's College of Medicine, where she's vice Chair for education.
- Penn State actually formed the 1st Medical department of Humanities in the Nation, and has continued to be a role model that will be as an ethicist.
- She gained her Phd. At St. Louis University and did her clinical fellowship at California Pacific Medical Center.
- Dr. Boldy teaches and directs the Penn State humanities and ethics curriculum, and also studies how humanities are utilized in health, profession, education and how to assess the outcomes.
- Keeping up with all the innovations in medical technology is hard as you know, it is only part of the challenge. As healers. We bridge the intersection of technology and humanity.
- We navigate complex social and ethical issues encountered by ill humans.
- For this medical, grand rounds. Dr. Goldby has courageously offered to help us think about 2 cases would have challenged all of us here at Uva back to hold things.
- Thank you for that introduction. Dr. Keel, will it be okay if I project?
- I'm Italian, so usually it comes naturally. But let me know if you can't hear me, and I will try to use one of these wandering mics that I guess I have to swallow in order to be heard live. So what I'm hoping to do today is have an informal conversation with you. We're going to do small group. We're going to do large group discussion. We are going to insert little micro lectures here and there, and I'm hoping that we can just talk about a couple of pieces that you had recently that have been challenging

to you. And so this all started, maybe a month ago, when I asked for your feedback about what cases have been challenging to you in the last few months that had been memorable, and I think that Dr. Williams actually has the 1st case to present. So what's going to happen is she'll tell us about the patient and then we'll talk about and see where we go. Oh, I don't so back in the spring, I was still an intern I was on Hemont for the 1st time, and I had a excuse me, I'm so sorry I need my notebook. So I'm gonna scribble notes.

- I had a wonderful 28 year old male who had autism, spectrum disorder, and really no other medical history. He was diagnosed with all. For the 1st time in July of 2023 had undergone treatment for that to include a stem cell transplant, and unfortunately had relapse, and was admitted to the hospital with nausea and vomiting, and really painful and he had a fever. So I sent to the emergency room. He got admitted neutropenic fever, infused bacterium bacteria.
- He was planning to continue treatment with the ultimate goal of pursuing car T therapy, which is kind of where he was at when I came on service. He had recently been selected and was bridging car t therapy.
- He was struggling a lot with pain. His absolute blast count was elevated throughout the entire time that I had him he was. I never saw the plate with above 20, but he was very motivated, and really wanted to do everything possible which is understandable for a 20 that you're over.
- Unfortunately, on around Day 35 of his admission. I went into his room one morning, and he wasn't really quite looking at me normally, and I asked him, but just frankly, Can you see me? And he said, No, not really. So ultimately. We got a head Ct. As well as effectively a hand scan because we still didn't have a good schools for his position on any antibiotics, and he was found to have a new subdural hematoma midline shift and ultimately was transitioned to Dnr. A. It previously been full quote.
- He was thought not to be a surgical candidate, and really had an overall very poor prognosis. He was grossly volume, overloaded and really suffering a lot. He was in a notable amount of pain. He couldn't even tolerate. On bedtimes most days there was a couple of factors that made his care really challenging. One was that he had not been very close with his family for some time with his girlfriend, who is equally young as the decision maker
- And he had been living with her family. But after the subdural some of his family members didn't come to the hospital, and was very angry with her for not sharing his diagnosis with them, and blamed her for them, and ultimately she felt a lot of pressure to continue things like Iv antibiotics and Tpn, because she thought that they would feel that she would hasten his death if those things were to be discontinued.
- Additionally, they had a lot of discussion about where he would want to pass. Ultimately, he decided he would not want to be a burden to her and wanted to pass in the hospital, and that was difficult, because she was not ready to transition them to purely comfort, care or hospice at that time, and that's something that becomes challenging when we're looking at any hospital metrics and wanting people to be in our A/C. Or officially in the hospital.
- Some members of the team had a lot of moral distress about his autism. We were concerned that maybe he didn't actually have the capacity to the decisions that he was making. And then we're learning also over on the autism spectrum.
- I didn't feel like that really contributed to him, not having capacity, but it it caused a lot of regrets for new people.

- And then ultimately, he did pass while in the hospital, still on Iv antibiotics and Tpm and I think there was a lot of tension at the end of his life. I think ultimately the goals that he had expressed the goals that she had expressed, and the goals of the home care system were hoping to communicate and weren't feeling in. So there was a lot of emotional distress because nobody was really on the same page, I think, with the care that we were providing, and it just was hard to watch a young person die who was really dedicated to.
- Yeah no. Sorry. Just clear for me. What is Dnra?
- Oh, so so we have different levels here in our A would be not pursuing chest compressions and intubation. Dnarc would be full comfort care whatever is going to help manage their symptoms or B is kind of somewhere in the middle. We're gonna change something. We're gonna come first.st It's often used as a transition point to allow family to arrive. For example things like Iv antibiotics and Tpn would fall into that category. And I think that's ultimately okay. And what is? So it's hard to answer a question. If you're not clear on what the question or problem is and there's a lot going on in this case. And so one thing that I think might be a good way to start is just by articulating what is the ethics question which, when I am doing ethics consult, and we get the call and a commission.
- Oh, to add this question what can I do to help with today? Part time sometimes particularly.
- Oh, I'd like to actually ask you to do like a long group or clean pair share and just take 3 min.
- Or the situation that we just heard. Maybe on the okay.
- Great. So just 3 min for trying to use this formula, which is maybe a challenging formula. But it will help you actually articulate an ethics question as opposed to other types of questions.
- Yeah. okay. yeah. But can you for the zoom people just like me? The same question again. Sure.
- And I, you don't think I can use. Oh, you can use this event. Okay yeah. Okay. Okay. Hello, Zoom colleagues. Oh, oh, I thought you said I had hello for those of you on Zoom. Sorry. Please disregard this. Those of you in the room. I've been asked to tell the folks on Zoom to please think if you can articulate an ethics question about the case that we just heard. Okay, thank you. yeah. Okay. Okay all right. Maybe we'll come back together.
- What kinds of what kinds of questions did you land on? I'm hoping I'm hoping you can share. I don't expect to get all the same questions, and if they're different that doesn't mean anything bad or wrong has happened, so don't don't feel shy.
- But are we sprinting mics off? If that was happening? Oh, yeah, Rice Crispy treats over here.
- Okay, wow, I can get it started. So one thing that I think is an interesting question that I don't know where where I would land ethically, is how you assess the capacity of a decision maker. Not necessarily your patient. So. You know what a you know is, how do you do that and respect someone who technically isn't your patient but decision maker for your patient.
- Yeah. So you didn't play by my rules. But that's okay. The the question is about, can we disqualify? Maybe a circuit decision maker who lacks capacity? We require patients to have decision-making capacity to make their own decisions. But we don't seem to have a parallel expectation for surrogates. Is that your question?

Yeah. So how? And maybe whether we evaluate capacity and surrogates great question cool. What else?

- We focused a lot on the either. The the conflict between the designated medical Poa, who was his girlfriend and the family, who kind of you know, wrote in at the 11th hour, and were expressing concerns and opinions that were discordant with the medical Poa's decisions as well as the previously expressed values of the patient.
- Yeah, so is the question about like, what is the role and value of the family's opinion? Yeah, like, does it matter? And if so, how much? Yeah. Yeah. Another great question.
- Okay, what else? No one's playing by my rules. That's okay.
- What else? I think one thing that played a part in his care that both parents asking was given his in a given, his prognosis and sort of the inevitability of him passing is it ethically justifiable to continue life-sustaining measures like the Tpn and antibiotics, potentially life-sustaining measures.
- Given that he's dying, is it okay that we are continuing low burden life sustaining treatment.
- Don't we do that a lot is it is the problem was the problem that it seemed to be in conflict with his wishes.
- I don't think it was in conflict with his wishes, but I think every time that he had to go in there and hang a new bag or get a new Id. It appeared to be contributing to his suffering, I see, and that was challenging for everybody involved. Yeah. And how did you evaluate his suffering towards the end. He wasn't speaking much. He was mostly just moaning and grimacing. He was clearly uncomfortable. Okay. okay? Great. So the ethics question is about, maybe like a non-maleficence question about possibly causing harm to the patient.
- For what benefit is that? Right? Okay what else?
- We talked about a little bit, and it's not going to follow. Thank you. That's okay. It's not going to follow the rules. So I'm going to apologize. But it's more. I think a lot of this comes to more of the moral distress that this case leads to. It's not so much the ethical question in terms of What how do you balance patient autonomy versus non-maleficence. But I think some of this is just the we see the writing on the wall, and the moral distress that it causes when we're doing things that are low burden, but just causes the distress of, we feel like we're just prolonging suffering. Yeah, and how do we, as a team support all of each like each other through that. That moral distress. Yeah.
- Yeah. So moral distress is when you know the right thing to do but feel like you can't do it. And the team it sounds like, especially if you felt like you were promoting suffering in your dying patient. That sounds like, of course, rife for moral distress.
- Dr. Williams, can you tell me more about the patients? So any other issues before I sort of circle back to the top any other ethical issues that you want to talk about for this case? Yes yeah. So I guess I see it as kind of a 3 way thing right? There's what is it that we perceive as the the patient would want in this situation? And then we have what the partner wants, and then we have what the family wants. And so, in my mind, the question is, how long is it ethically justifiable? Given those 3 way conflicts. How long is it ethically justifiable to tread water before we say, all right, we have to make a decision. Yeah how long interesting? So how long can we work to achieve consensus before we say we? We can't achieve consensus. And now what

we're going to do, what we think is right, we're going to do what we're going to default to what the patient wants.

- The latter. Yeah, okay yeah. So how long to let the process try to work?
- Okay. Good process.
- My question was, Oh, Dr. Williams, I was hoping that you could tell us more about what the patient wanted and his decision-making capacity. When I came on service. He was very clear. I think he absolutely had capacity. He outlined everything that he had been through, and how hard it was, and that he understood how hard car T was, but that he was committed to doing absolutely everything possible to survive.
- He was terrified of dying we talked about that almost every day.
- While he was still speaking. So I think he I think he knew he had a poor prognosis, and he was afraid of it, but he understood that, despite things being hard, he wanted to move forward.
- And then, the one time I saw that start to shift, I would say, is, as he was just having more and more pain.
- He wavered a little bit, and then the the Poa, who was the girlfriend reminded him, no patient. You always said you wanted to, Xyz. And then he would say, Okay, well, I'll I'll try for you. I'll keep trying and then after that was close to where he was at when I went off service, and then the the remaining week of his life. It doesn't sound like he was too verbal at all. And so the team was going off of his previously expressed desires to the poa.
- Yeah. His previously expressed desires which seem like an interest to pursue fairly aggressive interventions, to try to live even in the face of a very poor prognosis.
- Yeah, even when we told him he was still relatively alert. Actually, when he had the subdural, and we explained that to them, and he said, Well, maybe if I can get stronger. They could do a surgery to get the blood out of my brain so that I could do, car, T, yeah okay, so just if I can.
- This meeting is being transcribed got it so that elements of decision making the reason we care about decision making capacity is because of informed consent. It's 1 of the essential elements of informed consent and informed consent is the practical application of the principle of autonomy.
- Right? So we have this pie in the sky. Philosophical view that we should respect the autonomy of our patients, and the way that we operationalize that in healthcare practice is through the legal and ethical process of informed consent, and I differentiate them for a reason. I actually think they're not the same. I think the legal process of informed consent is about getting the patient to sign at the bottom of the document that says that they have read and understand. I think the ethical practice of informed consent strives for a higher a higher, a higher bar.
- So decision-making capacity is one of the the elements of informed consent. A patient can't give informed consent unless they have capacity.
- Capacity is different than competence.
- So competence tends to be stable over time and is determined by a judge. So we cannot typically declare our patients incompetent. Usually a judge would have to declare a patient, incompetent, decision-making capacity. On the other hand, waxes and wanes, you can be capacitated in the morning and incapacitated in the afternoon, and any fully trained physician is qualified to evaluate decision-making capacity. And there are 4 elements.
- Is this ringing a bell like, did you learn this? Amazing? Okay.

- And they are understanding, appreciating, reasoning, and expressing a choice. So since this is ringing such a good bell, help me help me. I think appreciation and reasoning are like the sticky parts of decision making capacity. So in this case, do you have any concerns about this patient's capacity, and if so, where are they?
- No concerns about patient's capacity? None say, can you say more than that? Here, I'll even give you a microphone? Yeah, invited. You've been invited. I mean, I I trust Dr. Williams's impression implicitly. It sounds like this. I mean this young gentleman clearly understood his diagnosis. He understood the courses of treatment through which he had progressed. He appreciated the tight and poor situation that he was in, but was able to reason like I'm a i'm a young man. I have. It sounds like he understood. He has potential life ahead of him and wanted to try to pursue that and express a choice to pursue those measures. So is there anyone who has concerns about this patient capacity?
- Dr. Hill does I'll keep. I'm gonna get back.
- That's sneaky. Okay yeah. It feels to me like, maybe he's expressing his girlfriend's reasoning rather than his own because the girlfriend is saying, No, no, remember, don't forget previously. You said you wanted to fight, and so, at a time when maybe he was thinking he was ready to transition to more of a comfort, care approach, the girlfriend is saying. But last week you said.
- What do you guys think about that? Yeah I was, gonna say, I think that's
- that's really tricky, because it's I think it's tricky, because she is both reminding him of something he's not remembering at the moment. But she's also helping to bring. She's also helping to speak. Born with him, and so is like, is she just helping him to say the things he's not able to say at the moment.
- Yeah, I agree with you that it is really tricky. In fact, some. I'm not sure if maybe you've seen this, but some living wills and advance directives now have a checkbox on them near the bottom. That says, like, basically, my surrogate is allowed to override anything that I've written in this advance directive, because what happens is that patients come into the hospital. They become unwell. They have no idea what's going to happen, as you know. And then the family member is the one who has to go on and live with whatever happened in the Icu. And so patients find that when they get to the Icu, and the situation is causing trauma for their family that they want to do what is comfortable, and feels right to the family member right? So that that appeasing is not the right word, but collaborating with a family member on what feels good and right for the family member is a value for them. And so I'm a person who has that box checked on my advance directive. Right? If I'm going to die, I want my husband to be able to live with the decision making that he made while I was sick in the Icu. He's the one who's got to live. I'm dead. And so it's okay with me if he doesn't follow the wishes articulated in my advance directive.
- And so the same thing could be happening here that this patient is saying you know, maybe I would be more inclined to transition to comfort care. But my poa girlfriend is going to have to, you know. Go on and live after I'm after I'm gone.
- One of the tricky things about decision making capacity not quite tricky. But a detail is that it's decision specific, so that the the capacity that is expected for a low stakes. Decision is lower, typically than the capacity that is expected for a high stakes decision. So if we are really clear that this patient has capacity, and he has, like autonomously and authentically and repeatedly expressed what he wants.

- And concurrently we feel like, maybe we are causing his suffering through these interventions. At the end of his life I would say, what we have is a conflict between autonomy and beneficence. Right? So.
- Childress Jim Childress, who, you know, you all know, probably said that there are 4 principles, biomedical ethics, autonomy, beneficence, nomalefence, and justice. And what's interesting about that is that that is really the framework that we have. It's the moral method that we have for solving ethical dilemmas so unlike in science, where there's just the one method, the scientific method in ethics, we have multiple competing methods. There's not broad agreement about which moral method is best.
- So, principalism with the 4 principles is one moral method. But there are others, actually. And I think that it's helpful to frame dilemmas within a moral method, because it helps us think more rigorously about the dilemma. So in this case, I think the conflict is between autonomy and beneficence. And so my question for you is which should prevail and why?
- And maybe you can go back into small groups for a couple of minutes to talk that through maybe 3 more minutes.
- That's beautiful. Which way to my office.
- That'll be hard. What are we going to ask about?
- Yeah it works. Yes I'm sorry what happened. And just and then she was like bye.
- Alright, maybe let's come back together, and you can tell me what you thought about which principle autonomy versus beneficence should prevail.
- So, Beachman, childress, do say that the principles are not lexically ordered, so they're not in an order of importance, which means that each principle is equally weighted which makes our lives harder. It'd be easier if they were in order of importance, and we could just say, Oh, well, autonomy is more important than beneficence, and so, therefore autonomy wins out, but they say, No, no, they are not in order of importance.
- I think, as a society we have ordered them actually and we have a very autonomy centric society. And we are sort of loath to override a patient's autonomy.
- Yeah, because because we're not all the same amount from America. Yeah, sure, that's true. Would you like to say more about that?
- Disturbed I think, classically, of Asian cultures having a different arrangement of economy less at the top. Yeah so plenty of people who are sure. Yeah, I agree with that. It seems like in our healthcare model. Here we are pretty autonomy centric.
- Where did you guys land on autonomy versus beneficence in the current case?
- Great we said that I think we said that beneficence is greater than autonomy, but that we all like acknowledge that this is a very tricky thing, and this happens a lot where those 2 principles are kind of at odds but just like in my gut, I feel like you can't go on, and you know go against beneficence in that context. And we also talked about how autonomy and like informed consent, can be really hard, because these concepts are so they can be so foreign to even people in the medical field like, if it's not your specialty, you don't know the ins and outs and all of the components that are involved, even when you go through the informed consent process. So it's like autonomy is like it's hard to assess, because they don't really have all the information.
- But it's tricky. Yeah, in autonomy. A lot of times we talk about the reasonable
- person standard, which is what we need to tell patients. What would a reasonable person want to know? Because we can't send patients to medical school right? So

that they know all of the same things that you know when they're making decisions, so they will never make as informed a decision as a physician gets to make. And so it's hard to. It's hard to find. The line, I think, is maybe part of what you're saying. So your group felt like beneficence should outweigh autonomy in this case, which would that mean like stopping the interventions and making him comfort. Care.

- Question, Mark, I think there's always what's it like?
- Why, we at Va. Have determined to have, like a Dnrp status, which is like somewhere in the middle of like doing everything and doing nothing.
- It's like, I don't know choosing. Okay, do you choose? Do you can do the Tpn or not? You can do the antibiotics or not. So you can put new Ivs in or not like like in this transition, there has to be a specifically stated outline of like, Okay, well, you know some of these things feed you whatever, but we're not going to like. Add any more antibiotics, or any more pressors in the Icu, or anything like that. There's got to be like, there's like a graded approach to like we're gonna do some of these things, but not others like we're not offering these other things anymore.
- Yeah. And I also, I feel like.
- I feel like the momentum of our healthcare system is with autonomy. And so I feel like, unless you make a really strong action to prioritize something else above autonomy. That's like, what's gonna end up happening without really trying to change that path. Yeah. And I think like I would in, I would never recommend overriding a poa and a capacitated patient to do something that both the poa and the capacitated patient are saying that they don't want right, and the our hospital attorneys and risk managers would like fall over if they heard that happening actually, which raises a question for me.
- What? The question has gone straight out of my mind. It was about, oh, why are we working with the Poa at all. If everyone agrees, the patient is capacitated, why is the poa involved in the care, like decision making about the care of the patient?
- I'm assuming for the end when he was not speaking anymore.
- Yeah. So so certainly, when when they came in together, it was very much of an active conversation between him and her about what they they wanted to keep doing
- He became less responsive after the subdural and then I went off service. About 2 days after that happened, and my understanding is that he was much less with it, for about the last week of his life from a Mentation standpoint. And so I think that contributed to some of the difficulty in the in the decision making, because it he he was not reliably contributing to conversation.
- So you switched over to the Poa when it seemed like the patient.
- There were questions about his capacity much more heavily.
- Yeah, okay, and tell. So I'm not a moral distress expert. But tell me about what ideas do you have about? What could this like? What can you do to support each other in your moral distress in the care of this patient.
- Thank you.
- I think something that we we all have a hard time doing is taking ourselves out of the decision. We put a lot of our own values. We put a lot of our own experiences.
- When we think someone should do something. It's like we see this 28 year old as someone who is very actively dying. And we see that writing on the wall. So in our heads. Why would we prolong this suffering process? Whereas his values and his experience and his girlfriend's values and experience is one that they want to try to do everything they can to.

- To see if they he can survive this, to make it to some treatment. So something that I've try to do on. I wasn't involved with this case, but with similar cases. When when I'm talking to team members, nurses, consultants, it's always saying trying to take myself out of the out of the conversation and equation, and saying, Where is where are they coming from? What's important to them?
- And why are they saying the things they're saying. And sometimes the answer is, they're saying it because they don't understand it, and that that's a signal to me that
- I need to spend more time with them, just talking them through what I'm seeing but a lot of times it's they fully understand it. It's just they're valuing things differently than I am, and it's making sure that I'm not trying to put my values onto them, and then just trying to make sure that everyone sees what their values are, and trying to be that advocate for them of saying this is what they value. And this is why we're doing that to try to live up to those values and not whatever our values are in this. In this situation.
- Yeah. at least, my understanding with moral distress. Is it 1st kind of came about as a concept in the literature and nursing predominantly because they're flung into those situations where they feel powerless to do the right thing because they're under the supervision of a physician, and I believe you know, once the thing that I know Jess does a good job of this already, so I'm sure she did this, but you know debriefing afterwards and saying it out loud, that you're feeling that sort of moral distress. I feel like we do a great job in our program of trying to talk after codes or other really challenging patient situations, and of course don't know the details here. But that communication. That it's a shared difficult experience, I think, allows people to not take that moral distress as a long term, dip in their resilience and their compassion and interest in patient care, but allows them to feel that medical community and just acknowledge the the challenge of it.
- So with my sort of straight clinical ethics hat on. I think what I would say in this situation is that the if the patient lacks capacity, and there is an appropriate, appropriately executed power of attorney document, and it sounds like the girlfriend, and the patient had really great prior conversation about what he would want, which doesn't often happen. That would allow the surrogate girlfriend to make substitute judgment surrogate decision makers. So there's a distinction in types of decisions that surrogates make and they are hierarchical. There's 2 ways. Surrogates can decide theoretically. The 1st is using the substitute judgment standard, which is when the surrogate decides, based on the known preferences of the patient, and the second is, when the surrogate decides, based on the best interests of the patient, which they do when the patient's wishes are unknown seems like this surrogate is able to do good, substitute judgment because they've had lots of prior conversations and was doing substitute judgment. And so I agree that it's sort of unclear to me what the role of the family should be. In this situation they need to be informed. But if there is a appropriately executed poa document and a surrogate who's doing good substitute judgment? I'm not sure why we wouldn't follow what the surrogate is saying.
- But can you talk to me about the pressures that we're making that complicated here.
- So the family showed up like I said, after the subdural, which was shortly before I went off service. So I met them, and they were still processing because they had no idea about his diagnosis, and they didn't understand what they were seeing, which looked really bad and my understanding from talking with the team that took over his care for the last week was that the decision maker may have been getting to a

point where she was ready to focus on comfort, and she was afraid to do that because she was feeling on some level attacked, or that the family was angry with her because they were just coming into this after it was kind of so far gone. They were mad that they hadn't known about his diagnosis, even though he didn't want them to know, and she worried that they would blame her if she did make the decision to move to full comfort, care and accuse her of kind of hastening. His death is what the team that took over shared with me when we reported with our students are we do? Is that, are we hastening death and killing the patients when we withhold and withdraw interventions allowing natural freeze it right?

- We'll see she's not concerned about. We think she's concerned about what it's family is going to see something we're giving us 5, bye, bye and I can see where sure. And what? What is our role as we communicate with the Poa about what her job is?
- Right? So I think a lot of times. We ask surrogates, what should we do in this situation? Instead of asking, What would the patient want? We say, what should we do? What do you think we should do, what should what should we do here? And I think the real question is, what would the patient want in this situation? I don't actually want to know what the surrogate wants. I want to know what the surrogate thinks the patient would want, and so I think in that context the healthcare providers can play a role trying to protect the patient and advocate or sorry, protect the surrogate and advocate for the surrogate's appropriate role in decision making.
- I feel like we have beat this case to a pulp, and we have 12 min left, which is a weird amount of time. And so I want to defer to others about whether we should try to sneak in the second case or not.
- And do you want to talk about futility at all with this? Sure. Do you think that there's a question of futility?
- I can talk about futility.
- Were there concerns about futility.
- think the family and the Poa?
- No matter. The hours spent did not understand that certain things or a child did you think change of service on the healthcare side and on their side, because we kept coming in every day and explaining something very grim. And so we became people who they weren't excited to see come in the room and ultimately it looked like a day or 2 before he asked. We had the palliative care team involved, they said, please just stop. Just stop having these discussions. Just let the family need and let them process, because our expression of what was child is not sinking in. And it was falling apart.
- Yeah. And so there are a lot of different definitions of futility in the literature, but the the one I like the best says that futility occurs when 3 conditions have been met. First, st there's a goal the patient's goal for care, usually an action aimed at achieving the goal and virtual certainty, the action will fail.
- So what that means is that futility? You can't have a conversation about futility without 1st having a conversation about goals. And so, if the patient's goal was what was, I don't want to make assumptions. Tell me what the patient school was.
- Yeah, okay. And the actions aimed at achieving those goals were the
- Tpn and giving him antibiotics for infection.
- Yeah. And scholars disagree about what the phrase virtually certain means.
- But do you feel like there is virtual certainty that those actions would fail to achieve the goal of living to nonspecific.

- We're all going to live for the next 5 seconds. Yeah, we can certainly achieve that. Yeah, I think you raise a great point, that is, is the goal survival to discharge or just survival for the next seconds or hours. Right on those 2 different goals for example, Cpr. May or may not be futile. And so with that definition of futility. The reason I like it is because it brings us back to goals. Right? It brings us back to talking to our patients and in a collaborative way, identifying what their goals are.
- So the patient's job is goals. And our job is virtual certainty, right? We know whether the tools in our toolbox, whether we have tools in our toolbox that will achieve the patient's goals. So if this patient just wanted to live as long as he could maybe treatment wasn't futile.
- If he wanted to survive, to discharge. Maybe treatment was.
- I think, to just another thing to bring up is like, what is this like? Live, be alive like, have a heartbeat, have like blood flow, have normal like is that living or like? What's their definition of living? Is it just being alive? Because they could have probably done that? Or does it mean? No, I want to live. I want to spend time with my girlfriend. I want to watch our movies that we love together. I want to do whatever Xyz like.
- I guess their goal again, do you just want to be alive or like, what does that mean to you? Yeah I think a lot of times. What can happen is we inadvertently conflate futility and worth.
- So sometimes in the hospital, when I hear clinicians say, treatment is futile, I think what they mean is, treatment's not worthwhile. And I think that's challenging, because worth is a subjective evaluation, right? And futility theoretically, should be more objective.
- Yeah, great.
- I have another definition, for that is to prolong suffering. I mean that sometimes helps patients also, or families to understand that.
- The intervention will not work. It will prolong suffering.
- Yeah, I don't know if you can comment on that. So you're saying, instead of using the language of futility just conveying, conveying to patients and families that the interventions they're asking for will prolong suffering.
- They need to speak their language, you know.
- Yeah, I tend to agree with you, I think, because of the lack of agreement about what futility is.
- In some ways it's a little like the F word in medicine. It carries this big gravitas like it's a big deal if you say treatment is futile and concurrently, there is not broad agreement about what futility means, and that feels like a dangerous combination to me just even amongst ourselves, let alone in communicating with family members.
- Yeah. And now I think we've thoroughly bludgeoned the case.
- Thank you. Thank you for your time.