Medical Futility in Texas - Again

Dr. Laura Miller-Smith discusses the case of Tinslee Lewis, a baby in Texas who is at the center of a controversy about medical futility.

Featured Speaker:
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Laura Miller-Smith is a pediatric intensive care physician and author of "Ethical Issues in the Pediatric Intensive Care Unit"

Transcription:

Welcome to the Peds Ethics podcast, where we talk to leaders in pediatric bioethics about a hot topic or a current controversy. Here's your host, John Lantos from the Children's Mercy Bioethics Center in Kansas City.

John Lantos, MD (Host): Hi, this is John Lantos from Children's Mercy Hospital in Kansas City, Missouri, bringing you the pediatric ethics podcast. Today, we are thrilled to be talking to Dr. Laura Miller-Smith, the Chair or our hospital ethics committee and a pediatric ICU doctor. We're going to talk about the controversial issue of medical futility and in particular, a case that's been making headlines from down in Texas, a case involving a baby named Tinsley Lewis who has been critically ill down there for quite a while. Welcome Dr. Miller-Smith. Thanks for joining us.

Laura Miller-Smith, MD (Guest): Hello, great to be here. Thank you.

Host: I know that you've been thinking about the Tinsley Lewis case for a while. Can you just summarize for our listeners the medical facts of the case and the outlines of the controversy?

Dr. Miller-Smith: Absolutely. Fortunately, for a period of time, Cook Children's Hospital was given permission from Tinsley's mother to give some information on this case. There is some information online about what's been happening for Tinsley over the last year. So, we are not completely in the dark. She's a little girl who is now a year old, born last February. Unfortunately, she has significant congenital heart disease called Ebstein's Anomaly that was diagnosed prenatally and then she was also born prematurely and had respiratory distress syndrome at birth and has since developed severe chronic lung disease and severe pulmonary hypertension. And unfortunately, the surgical palliations that can be done for Ebstein's Anomaly are significantly more complicated when you have those respiratory diagnoses. She's had multiple surgeries done. One was performed in July that resulted in a cardiac arrest in her postoperative period and she spent some time on ECMO support, so basically heart lung bypass, very heroic measures to keep her alive. And then had an additional –

Host: ECMO is pretty common after cardiac surgery.

Dr. Miller-Smith: It's not uncommon. That's correct. But even at the time, the physicians have stated that they were concerned about her long-term prognosis and did feel that that was heroic for her.

Host: Did they think that she had a neurologic injury at that time?

Dr. Miller-Smith: I do not believe so. I have not seen any evidence of neurologic injury reported anywhere. That she has the capability of interacting with her environment, however, her pulmonary hypertension is so bad that she has been on continuous high dose sedative infusions and also most often chemically paralyzed because of any significant movement has resulted in worsening cardiopulmonary function. So, it sounds like around September, with not being able, she was able to come off ECMO support but not able to wean on ventilator support. It is around that time that the family was probably not first, it was probably a conversation that was occurring much before then but around that time, the family was being counseled that placing DNR orders may be in Tinsley's best interest and beginning of October, it was escalated to the ethics committee.

The family didn't want to engage with the ethics committee. The hospital reported that they did try to reach out to Tinsley's mom, and she did not want to meet with them. But then the hospital followed the Texas advanced directive act that if a physician wants to place limitations to advancement of care or wants to withdraw technology, that it needs to be reviewed by the ethics committee.

So, at the end of October, the ethics committee convened to review Tinsley's case. Tinsley's mother and grandparents were present to represent their side of the story. But after getting all of the information, the ethics committee did recommend that technology be removed.

Host: So, they actually said stop the ventilator and let Tinsley die?

Dr. Miller-Smith: And allow her to die a natural death. Correct.

Host: Okay. What happened next?

Dr. Miller-Smith: Consistent with the Texas Advanced Directives Act, the hospital gave the parents or the family ten days to reach out to other facilities to accept Tinsley in transfer. The hospital, however, had already reached out to multiple facilities so by the time this ten day period was over, there was 20 hospitals, very well-respected facilities that had agreed with Cook Children's assessment of the case and had refused to accept Tinsley.

Host: 20 hospitals said no, they don't want to accept her in transfer.

Dr. Miller-Smith: That's correct. So, Tinsley's mother reached out to the Texas Right to Life Group to help advocate for her belief that there was still hope for Tinsley to recover or at least to stabilize enough that she could eventually be discharged from the hospital for palliative care. And since that time, the family has been appealing the case in court and the Cook Children's has not been allowed to remove technological support from Tinsley. So, she continues to be technologically supported at their hospital.

Host: And that is now four months after the ethics committee recommended that her life support be withdrawn.

Dr. Miller-Smith: That's correct.

Host: So, how unusual are cases like this?

Dr. Miller-Smith: Well I – you read the story and I imagine any intensivist can relate to Tinsley's case. I mean just different children's stories pop into my head that seem very similar. So, having cases that we are not able to cure or even palliate enough to get a child discharged from the ICU is not uncommon. Most of the time we can get parents over time, to work with the healthcare team to allow a natural death in a way that's consistent with their beliefs. On some more rare occurrences, we will have disagreements with the family that may eventually escalate to what we may call an intractable disagreement where we have to start bringing in the ethics committee or other psychosocial supports within the hospital or even reach out to other facilities in order to get them to weigh in on the disagreement. But again, most of those disagreements with time, and really good communication, we're able to work out without the case being escalated either to the media or to the courts. It's very rare that a case like this is going to be escalated outside of the hospital walls.

Host: And how do they usually resolve in your experience? Do doctors just continue treatment or do parents finally come around and accept the withdrawal of life support?

Dr. Miller-Smith: My experience is the majority of time; parents just need a little bit longer to reach the conclusion the healthcare team has already reached. Typically, that's a matter of weeks unfortunately sometimes it could be months. But if we're able to support the child's body in a way that is not detrimental to them, like we are not causing undo pain and suffering; we'll continue to do that to allow parents to see what they need to see to understand why we've reached the decision or that we're making the recommendation that the best option is to withdraw technology and most families are going to understand that. Sometimes the progression of the disease is also going to just highlight to them that the patient's going to become increasingly unstable and they'll recognize that the child is actually dying.

Host: There was a famous case, famous like got a lot of publicity in the UK a couple of years ago Charlie Gard. But he had a degenerative disease that was just getting worse and worse over time and that was the natural history. Is that also true for this Ebstein's Anomaly that Tinsley has?

Dr. Miller-Smith: The Ebstein's Anomaly is not necessarily degenerative. The problem is that the palliation that she has received is incomplete. But overtime, she will likely develop worsening pulmonary hypertension. Certainly being maintained on a ventilator, likely on high support is going to cause worse lung damage and eventually her heart will likely fail. But with how advanced technology is nowadays, we really do have the ability to sustain life for this little girl for quite some time. Not knowing the nuances of her case, I don't know how long the physicians there could predict that. Predict how long they could sustain her but so yes, it would be degenerative over time, but I imagine that this excellent hospital would be able to keep her body supported for a very long period of time.

Host: Now would she be a candidate for a heart transplant?

Dr. Miller-Smith: She would need to have a heart and lung transplant for her size, that is an incredibly limited resource. And I do believe that Cook Children's reached out to facilities that offer heart lung transplants and they declined to offer that therapy or that intervention.

Host: So, let's step back for a minute from the details of her case and talk about the Texas Advanced Directive Act the law that permits physicians to go through this process and then essentially override or unilaterally make a decision to withdraw life support. That's unique to Texas, correct?

Dr. Miller-Smith: That is unique to Texas. There's no other state that has similar legislation. I believe it's been tried in Virginia but not passed. But yes, very unique to Texas. And I believe it passed in like 1999, does that sound correct? I think it has been heavily debated since that time.

Host: Yeah, what are the implications of a case like this where the hospital goes through the process, meets all the legal requirements and then the courts still hold up the plan to withdraw life support?

Dr. Miller-Smith: Well I think the intention – so interestingly when the law was first passed, there was agreement from the Right to Life Groups that are currently somewhat in opposition of the law. The benefit to them at the time, was that it was a transparent process for families and patients so that there wasn't concern of unilateral decisions being made that they weren't aware of and that they could be aware of what decision – what the process was for the decision. The benefit for physicians was that as long as they followed the process, they were not legally at risk, that they were being protected from any suits against them for withdrawing technology. So, it seemed to be benefit to both families, patients, and also to healthcare providers.

So, certainly concerning at this time that the law that was supposed to allow physicians to do this without risk of having to go to court, that no longer seems to be the case. The families are able to take this to court and to continue to appeal the cases, leaving the healthcare system kind of in this limbo. So, it really just kind of defeats the initial intention of this act by allowing all these cases to be appealed the way they are. And certainly, there's lots of people who think that the act needs to be revised or eliminated.

Host: And when you have a case similar to this, a case where you and your colleagues think that it is in a child's best interest to withdraw life support and the family doesn't agree; what is the most troubling aspect of that for you and your team?

Dr. Miller-Smith: I think the most troubling aspect is that we worry we may be causing undo pain and suffering to the patient in order to meet a family's unrealistic hopes. While I think certainly there's always a concern in the back of our heads somewhere back there that there may be legal implications as we get into these intractable disagreements; the healthcare providers I know are really focusing on what is in the best interest of the patient. I particularly feel for bedside staff who are in the rooms of patients 24 hours a day who are being asked to do the blood draws.

Host: The nurses.

Dr. Miller-Smith: Exactly, the nurses, and even respiratory therapists, anyone who is in there on a regular basis who are actually fulfilling the physician's orders and feel like they are causing harm to the patient on a regular basis. There's a lot of moral distress that comes from that. And I know that's a big concern now at Cook Children's for their staff. We talk about the resources that go into some of these futility cases. I think many providers are less concerned about the financial resources but it's the – one of our most important resources and that's our staff. We need our nurses and our physicians to be able

to come back and do this work every day. And when you feel like you are causing harm to patients, that can have a huge toll on the healthcare provider's wellbeing and lead to burnout.

Host: Have you ever had a case where you were certain that a baby was going to die, and they surprised you and survived to leave the hospital?

Dr. Miller-Smith: Yup and that's – there's where the challenge is. I certainly have. I can think of one case that pops into my head where I counseled a family multiple times that the likelihood of that child every leaving the hospital was close to nothing. But that we were willing to keep on going because I didn't think that the pain and suffering that the child was experiencing was worth really battling that family about. I felt we could continue, and they would see and remarkably, the child got better, and another care provider sends me pictures. It does and I think that's – when a physician makes the recommendation that technology is no longer in the child's best interest; it's not something that they typically come to lightly. In the media, on the Tinsley case, there's a lot of implications from folks who don't know the situation, that the healthcare providers decided one day that this was futile. But this is something that has been going on for months and months there. And they yet to have evidence to the contrary. But I think all critical care doctors can think of a time where they were wrong. So you do have to be humble and take that into consideration.

Host: And that's one of the reasons why the law stipulates multiple layers of review I suppose to make sure it's not one doctor making an off the cuff decision or hastily.

Dr. Miller-Smith: Right and I think right and then requiring or allowing families to reach out to other facilities to ensure that there's other people who are reviewing it. And if someone else thinks –

Host: There's a lot of safeguards built in.

Dr. Miller-Smith: Yeah, absolutely.

Host: Well we will certainly be following this case and perhaps we'll give our listeners an update if the case is resolved one way or the other either Tinsley gets better and goes home or sadly if she passes away. Thank you very much. We've been talking to Laura Miller-Smith a Pediatric Intensivist and Chair of the Hospital Ethics Committee here at Children's Mercy Hospital in Kansas City, Missouri. This is the Pediatric Ethics Podcast coming to you from Children's Mercy Bioethics Center. I'm John Lantos. Thanks for listening.