Ethical Dilemmas in Fetal Medicine

Dr. Steve Leuthner discusses the ethical questions surrounding advances in prenatal diagnosis and in-utero treatment of fetuses.

Featured Speaker:
Steve Leuthner, MD

My experience in neonatal practice, perinatal consultation, and palliative care/end-of-life care, both clinically and academically, leads me to partner as best I can with parents in any treatment decision for their child. I believe in open, honest communication about values as much as medical procedures. We service our patient's best by working as a team, which includes all health care professionals and parents.

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 everybody, it's John Lantos from the Children's Mercy Bioethics Center bringing you another episode of our Pediatric Ethics Podcast Series. We're talking today with Dr. Steven Leuthner, from medical College of Wisconsin, a Neonatologist and expert in fetal healthcare. Dr. Leuthner is a Professor of Pediatrics at Medical College of Wisconsin and was one of the pioneers in the field of fetal medicine. Could you tell us a little bit about how fetal medicine developed at Medical College of Wisconsin?

Steve Leuthner, MD (Guest): Sure. When I first arrived as a graduating fellow from my neonatology fellowship, I had the experience of doing a few prenatal consults and when I arrived at Children's, I recognized that there wasn't a good coordination of care between the maternal fetal medicine physicians and the neonatology group in best helping families understand when they have babies with birth defects what was going to happen to their baby. Things were very spotty in how consults occurred. So, in partnering with the maternal fetal medicine physician we started a process where I would be the person who they would call to help support in consults and then it would be up to me to help guide whether we wanted pediatric surgery, urology, neurosurgery or other folks to participate in the consultations.

One time I was talking to my department chair he got very excited about the idea and he decided he's going to help fund some part of this project and I literally the next day after talking to him got a call from our administrator saying I have a salary slot for a nurse coordinator for my program. And so I give a lot of credit to Dr. Kleegman and we hired a nurse and that's how the things began.

Host: So, before this started, if there was a situation where diagnosis had been made of a fetal abnormality; what would happen? All the counseling was done by the obstetrician?

Dr. Leuthner: Yeah, most of the counseling was done by the maternal fetal medicine physician

depending on the situation, they seemed to at times call a pediatric surgeon or somebody for help, but they seemed to feel like at the time that they knew enough about things to counsel. So, I think that this obviously left the families and women with probably some misinformation, not enough information because obviously the maternal fetal medicine physicians acknowledge that they can't keep up with every fetal birth defect and what's happening in the world of neonatology at that time.

Host: So, what are some of the ethical issues that arise that are unique to fetal medicine, different from obstetrics and different from say neonatology, your specialty.

Dr. Leuthner: I think that the biggest issue obviously is that here we are called in as a pediatrician expert at some level to help engage the family in understanding something that's happening to their baby, their fetus and baby to be and so clearly,

Host: The language is important there.

Dr. Leuthner: Well it is interesting, yes, we routinely call them to the parents their babies, but we need to acknowledge depending on time in gestation there's a lot of other issues that come up. But that said, you could see where at times there were potential for difficult decision making for the pregnant woman who is really trying to make a decision as a mother for her baby yet in a situation, she's not officially a mother yet from the process of birth. And then obviously, as therapies moved forward in this field; the ethical issue of interventions and they could be anything simple from steroid injections for helping mature the lungs to obviously major surgical endeavors that are now occurring in the field.

But has always historically been set up as this maternal fetal conflict and I think that yes, you can easily set things up that way but in another way to try to think about it is how do you set it up as here's a mother who loves her baby and is wanting to do what's best for baby but has to take on risks that no other mother has to if the baby is already born. And it leads to very interesting discussions and developments of how do we balance those risks.

Host: Can you think of a case or two maybe from the early days of this thing to where it suddenly hit you that wow this is more ethically complex than things I've done before or raises different ethical issues?

Dr. Leuthner: The cases that come to mind mostly are those where we are dealing with a woman who would have to undergo a pretty serious operative procedure and a baby who we're not sure we can really help or do anything about. One of the examples that we were trying to be a little innovative in once was we had a baby with a sacrococcygeal teratoma who was developing severe hydrops fetalis which means they are essentially in congestive heart failure and have fluid everywhere in their body where it shouldn't be, and the baby is dying. And at that time, we were discussing what can we do for this and as an innovative thought, one of our maternal fetal medicine physicians knew of some interventional radiologists who did embolization of tumors. So, we started some discussions and we then had discussed with this mother what if we tried embolizing this tumor; could we help reverse the hydrops fetalis.

Now there had been attempts in the past radiofrequency ablation of these tumors and it did harm to those babies. Because it tended to burn – you can't control the spread of the burn or damage being

done. So, we did make an attempt at this and I just remember really struggling with the maternal fetal medicine, the surgeon, a pediatric surgeon involved who obviously the people who deal with the sacrococcygeal teratomas after birth and working with this mother, recognizing is the father – there's the mother father relationship that is affecting the decision making, MFM who is excited about this concept.

Host: Was this going to be an open procedure or laparoscopic?

Dr. Leuthner: No it was going to be laparoscopic. We did make an attempt and it took a while. It wasn't nearly as successful as everyone thought. And in the meantime, they also did a periumbilical blood transfusion for that baby because the baby was severely anemic which is what happens with these tumors causing hydrops. People were excited over the next week because the hydrops seemed to be resolving a little bit. But it was unclear whether it was from them embolization or whether it was from the transfusion. It became clear a week later when the hydrops became worse again. And then of course, I watched this mother come back with chorioamnionitis an infection and us having to now help get her through this, delivering a baby who is now going to die. And so that's a case that is on my mind of one where I see so many different ethical issues that are very intriguing to me about innovation, about pressure from husband or not, the excitement of doctors to try to help, a mother who wants to help.

Host: At the time, this was a highly experimental procedure. Had it been done other places?

Dr. Leuthner: No, this form of embolization had not been done at any other place of the fetus.

Host: And how did you explain that to the parents? Did you tell them you are the first human beings on earth ever to undergo this procedure and we have no idea whether it's going to do good or harm?

Dr. Leuthner: We – yes, we did. In simple words, yes, we talked to the family. We told them that their baby – we knew with certainty their baby was going to die in utero if we just let nature take its course. The baby was a little bit too early and the thoughts were even delivery would lead to a neonatal death. And so, we told this mother we have people who are skilled at these procedures in different situations but it's a different patient population. It's never been done in this situation. Something similar has been tried and it didn't work but it was – and it caused harm in different ways that we don't anticipate this would. So, it was a very complex multiple conversations over time.

Host: And did you also anticipate the possibility of the chorioamnionitis and the risk to mom?

Dr. Leuthner: We did talk about infectious risks with any time we're sticking a needle into the womb, so that was known.

Host: So, what did your team take away from this? Did you say we learned a lot; we'll do it better next time? Or did you say, that was terrible, we're never going to do that again?

Dr. Leuthner: I think that it was an example where I saw some physicians who were struggling to give up the idea. And wanting to do perhaps another try on this mother.

Host: Another try of embolization?

Dr. Leuthner: Yes or even the radiofrequency ablation – so there was disagreement among the team and there may have been a little cultural issues involved. So, it was a complicated case. The one thing I made sure we did was we had some arrangement with one of our IRB committee to help us make sure we're going to be on the table if we are trying something new, so we had some discussions with them.

Host: This was not part of a research protocol?

Dr. Leuthner: It was not part of a research protocol at the time. There was no protocol at that time.

Host: So, how do you decide now in a similar situation, if there's a fetus with problems that are likely lethal, and somebody proposes a previously untried, unstudied intervention that may be the only hope? Who gets to decide whether to do that?

Dr. Leuthner: It's an excellent question. That exact situation has not arisen since that time. In that sense. I do think

Host: It probably has in other places.

Dr. Leuthner: It probably has in other places. And I think that the most important thing is that from what I've learned from it is we need to all be able to try to listen to each other. We do need some level of oversight and support when there is conflict amongst the care team. So, from that perspective, I think that institutional oversight is somehow critical to make sure we're not overstepping boundaries.

Host: And this field is growing pretty rapidly isn't it, fetal medicine?

Dr. Leuthner: Yes. It is a growing field. It's continuing to advance with innovative attempts at things. and I think the field is doing much better as far as trying to organize them as research once some level of feasibility is thought to exist.

Host: Tough to do randomized trials.

Dr. Leuthner: It is, yeah most of the research projects are not going to be set up as randomized trials. Most are going to be set up as case series and with a potentially – if it is a randomized trial, it would have to be a randomized trial of this intervention versus the no intervention to follow along with whether there is benefit or not.

Host: Do you see some advances on the horizon? Do you think we will be curing some things that we now can't cure?

Dr. Leuthner: Well I think that the areas that I see people researching right now or at least beginning to move forward with projects that – which I have differing levels of expectations on whether we are going to prove positive or not on are the RAFT trial which is the renal ammoniagenesis fetal therapy. It's for babies who have no amniotic fluid, no kidney disease and we do amnio infusions on the moms serially over time in order to try to help the lungs develop, knowing those babies will need dialysis and kidney

transplant at some point throughout their life.

Host: And this would be a similar situation where without intervention –

Dr. Leuthner: Without intervention, those babies die because the lungs don't develop, and the babies have no chance of survival even with our neonatal treatments. So, that's one study that is being put forward and it will be interesting to see if that advances that. The other study that NAFNET which is the North American Fetal Treatment Network is doing is collecting data right now and a registry on hydrocephalus, trying to – and I think that project, I really appreciate how systematic this project is being set up because the first step is a repository of data on imaging and looking at neonatal outcome in order to try to pick the patients who might actually have aqueductal stenosis as their cause of hydrocephalus and at which point then there could be potentially a fetal intervention to try to open up the aqueduct.

Host: A shunt? Or a dilation?

Dr. Leuthner: A laser procedure to try to open up the duct. So, again, it's being done I think in a appropriate systematic way whether we are able to technically do this or not over time and will be something that we will see.

Host: Well we appreciate all the work you've done so far. And admire the creation of this National Fetal Therapy Network. And look forward to seeing whether you can solve some of these problems.

Dr. Leuthner: Thank you. I'm glad to be here.

Host: Once again, Dr. Steve Leuthner from Medical College of Wisconsin. A Neonatologist and one of the pioneers of fetal therapy in fetal medicine. This is the Pediatric Ethics Podcast from Children's Mercy Hospital Bioethics Center in Kansas City, Missouri. I'm John Lantos. Thanks for listening.