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### Challenges Faced in Vascular Access Care: A Patient Case

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Dr. Jennifer Caudle: Welcome to Vascular Viewpoints on ReachMD. I'm your host, Dr. Jennifer Caudle, and joining me today is Dr. Kevin Baskin, an interventional radiologist from Pittsburgh. Today, we will review a memorable patient case of a 7-year-old boy with intestinal failure due to short gut syndrome and the complex vascular access considerations faced by Dr. Baskin's team over a protracted period of time.

Dr. Baskin, it's really wonderful having you on the program today. Thanks for joining us.

Dr. Kevin Baskin: Well, thank you, Dr. Caudle. I'm really looking forward to this conversation.

Dr. Jennifer Caudle: Absolutely. So, let's introduce the case. Can you give us some background details on this patient and the circumstances that eventually brought him to you?

Dr. Kevin Baskin: Sure. This 7-year-old boy had a very compelling and emblematic challenge with his central venous access. He was born with gastroschisis. This is a congenital birth defect in which the abdominal organs like the intestines and sometimes the stomach and liver protrude outside the body through a hole in the abdominal wall near the belly button. This leads to many problems with intestinal function, including lack of motility, obstruction, adhesions, and necrosis for that which protrudes. When the intestines don't function well or when portions of the gut have to be removed, they may not absorb enough nutrients to sustain the patient. That was the situation with this child. From the time of his birth, he needed to receive nutrition through his veins to stay alive. This is what brought this boy to me.

Dr. Jennifer Caudle: And just to ground us on the complexity of this case from a vascular access standpoint, what complications did this patient face early on along the way towards a more stable vascular solution?

Dr. Kevin Baskin: Well, Dr. Caudle, I could probably sit with you for the better part of the day just listing the things that can go wrong, but I'll just mention a few of the big ones. The nutrition these patients need is delivered through central venous catheters, plastic tubes in the veins leading to the heart. These patients spend hours each day with their catheters hooked up to a pump to deliver the nutrients and fluids they need to stay alive. Many of these children spend years, even lifetimes, needing these lifelines. Beyond the challenge of being hooked up to a pump to get nutrition, which seems like it should be enough, there are so many things that can go wrong, either with or because of these complications. They can get caught on something and pulled out accidentally. They can crack and break. They can cause reactions in the body that lead to positive material or clots that can block the catheter, or even block the veins. This boy was dependent on his central venous catheter for Total Parenteral Nutrition or TPN. If he lost access, he would not survive more than a few days. He had liver failure as well because the long-term TPN lipids or fats that he needs for nutrition, damaged his liver. For these reasons, he needed a multivessel transplant, a new liver, small bowel, and pancreas. And, by the way, just to illustrate the precarious position these kids live in, one indication for transplantation is impending loss of the venous pathways needed to deliver nutrition. If the patient loses many venous pathways, some of which are also necessary for the transplant operation itself, they may not be eligible to even get on or stay on the transplant list. By the time this boy first came to me, he had already lost two of the six major pathways through the catheter complications. And I haven't even mentioned yet what is perhaps the most terrible complication of these, catheter infections. Catheter-related infections happen so often in these patients and because any one of them can be fatal. These patients can be quite sick with these infections. Each one may require treatment in the Intensive Care Unit with life-supporting therapies in addition to the antibiotics needed to help fight the infection. Even when the infections are treatable, treatment may include removal of the

catheter which can, in turn, lead to loss of critical venous pathways. When the catheter is out, it may be difficult to provide adequate nutrition and other medications until the infection is cleared and it is safe to put a new catheter in.

Dr. Jennifer Caudle: On average, how often did this patient need to come back just to receive new lines, and what kind of process was this each time?

Dr. Kevin Baskin: Well, Dr. Caudle, from the time of his birth, he never went more than two months without a catheter-related bloodstream infection. By the time he was seven years old he had had more than 50 of these catheter labeled infections. Each time a catheter needed to be removed, he would come to me to have a new catheter put in. This usually meant deeply sedating him in the interventional suite and using ultrasound and x-rays to find an open venous pathway that would allow me to puncture his vein through the skin and insert a catheter through the vein right up to his heart and then securing the catheter so it would be protected from being accidentally pulled out. At times, when critical pathways are closed, I have to use more extraordinary methods to get through the veins or to open them up enough to get the catheter through. So, these procedures might take less than an hour or sometimes many hours to achieve successful access.

Dr. Jennifer Caudle: It almost goes without saying, but what impacts did all of this have on the patient, his family, his caregivers?

Dr. Kevin Baskin: Dr. Caudle, it will break your heart to hear some of the stories these patients and their families tell me. They miss work and school, sometimes having to travel long distances to find a center for treating these conditions. Families get split up, people lose jobs, insurance runs out. There are very real human costs attached to these problems and parents can feel pretty bruised and battered.

Dr. Jennifer Caudle: For those just tuning in, this is *Vascular Viewpoints* on ReachMD. I'm Dr. Jennifer Caudle and joining me is interventional radiologist Dr. Kevin Baskin. Today we're reviewing a patient case with a complicated journey through vascular access care.

You know, you mentioned so many aspects of that story, the child's journey; talking about your perspective, what care coordination challenges did you encounter either at this point or throughout, and did they expose any practice improvements that sort of led to this idea of communicating better within care teams?

Dr. Kevin Baskin: We continue to face many hurdles in delivering optimal care to patients. Care can be quite disjointed, and policy and procedures can differ widely within the same hospital not to mention from institution to institution. The number of different providers that can be involved in critical decisions, without communicating with each other, can be staggering. For care that happens in the hospital, reporting of complications to National Surveillance Networks is full of inconsistencies and gaps. Half of long-term central venous care happens outside the hospital where there is no formal system of surveillance. So, giving accurate evidence in or out of the hospital about catheter-related complications is enormously challenging. Unless there is actual pus oozing from the wound, it can be very difficult to determine when an infection involves the catheter, or the infection is elsewhere in the body.

Dr. Jennifer Caudle: Looking back over this case, what do you find worked well and brought out the best of what vascular access care can provide for patients like this patient?

Dr. Kevin Baskin: One of the things that we try to do, Dr. Caudle, is to focus on the critical components of care and not who delivers those components. We need to make sure that we cover the basis for safety and effectiveness and that we partner with the patient and honor their experience and the role that they play as providers to themselves, or to their family, or their children. When we work in this way, when we focus on the components of care rather than the care providers, I think that's when we have the best chance to see the value of working in partnership in a coordinated effort to deliver care across the institution and across the health care domain that we can all learn from and that we can help use to improve delivery of quality care.

Dr. Jennifer Caudle: Great. Before we wrap up our discussion here, on the other side, what do you feel could have been approached differently such that others in our audience can potentially draw from those issues to improve their own practice?

Dr. Kevin Baskin: We can start to move in a more positive direction, and really the key to unlocking that issue is quality data. There is a national imperative to improve access to what's called interoperable data, that is, data that can be entered once and used many times and shared between providers and patients so that over the arc of their whole care, not just one catheter, but their whole venous lifetime, is where we can use that data to guide us in improving care in a coordinated plan.

Dr. Jennifer Caudle: Well, with those final takeaways, I would like to thank our guest, Dr. Baskin, for walking us through his memorable patient case and highlighting both the successes and setbacks experienced along the way. We learn so much from these stories and how they relate back to our own experiences and, Dr. Baskin, many thanks to you for sharing this with us today, and thank you so much for joining us.

Dr. Kevin Baskin: Thank you, Dr. Caudle, for allowing me to share this case with you.

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