Challenges in the Management of Intestinal Failure in Preterm Infants

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I'm excited to talk about another topic that I'm passionate about and this one is definitely more clinical. Okay, I didn't talk about this too much before, but since I'm talking about our intestinal failure program at Texas Children's Hospital, I just wanted to give you an idea of what our unit's like. We're 195 beds, over 200 if you count our cardiac ICU beds, and we have a large inborn unit as well as a referral center. So, we do get babies from all over the country and the world for management of intestinal failure. They usually have short bowel syndrome, can't tolerate enteral feedings and need long-term TPN and management. And I'll get into that.

We have 56 physicians at our medical center location and that's a lot. The good news is we all participate in making our guidelines every year, nutrition guidelines, GI guidelines, respiratory care guidelines, so there's a lot of buy-in. We do try to practice in a similar fashion, knowing that the guidelines maybe cover 80% of the population and you'll have that 20% variable where babies won't follow the guidelines. We also have a large group of nurse practitioners, nurses and respiratory therapists, social workers. I told you about our dieticians and I started the program with Dr. Steve Abrams back in, I think, 2010. I ran the intestinal failure program for many years and then Dr. Premkumar joined as codirector and now he's running the program and I'm the associate director. We also now have Elena Itriago and Dr. Emily Sabatini who are also rounding in the NICU on our intestinal failure babies. Sometimes I call them IR and then my colleagues are like, what, you mean interventional radiology and I'm like, no, intestinal rehab. So, I'll try to be consistent in how I mention this today. But we have a multidisciplinary team. I mentioned our dieticians that are very talented and help us with these babies.

I do have a disclosure in talking about the preterm neonate postsurgery and how to feed and give nutrition to these babies. There's not a lot of evidence published. What I'm going to present to you today is a lot from our experiential data at Texas Children's, for all these years now where we've had so many babies we've cared for with intestinal failure and specifically preterm babies and then, where there is evidence, I will present that. I also, at the end, will have a QR code for the guidelines in case you're interested in seeing them. I'm not saying they're perfect, but our goal is to practice in a similar fashion based on our experience and then study that and then adjust our practice based on study outcomes.

We do have intestinal rehabilitation rounds once a week. We see babies Monday through Friday as new consults, but at any given time, we probably have 40 babies. Some are preterms, some are term, but 40 babies that we consider with intestinal failure. That means they are parenteral nutrition-dependent; not tolerating a lot of feedings; they can have acquired bowel disease like from NEC; they can have surgical bowel disease; they can have congenital bowel disease like atresias or complex gastroschisis with atresias. We sit down and what's really great is it's us, our dieticians, the surgeons. Surgeons are really important. They help us figure out, you know, hey, we've medically managed this patient long enough and we think this is a surgical issue now and so it's very helpful to have pediatric surgeons there. We have the primary doctors that are taking care of the babies. In this role, although I'm a neonatologist and take care of all babies, and as the intestinal failure attending for the week, I'm only taking a look from an intestinal failure perspective. You have the primary team there, we have gastroenterology attend, whether that's attendings or their nurse practitioners, and then we have care coordinators. We send a good number of babies home on parenteral nutrition and I'll talk about that. That takes a lot of care coordination. I would say we talk about 10 to 12 babies, it's a lot, in an hour. We review imaging, we go through the medical record and have discussions. We are never bored! We're always expanding, so that keeps us very busy.

This is something that I published with Misty Good, but basically our intestinal failure team, we can't see every baby in the NICU and we don't want to. You know, we have a lot of colleagues, all of our neonatology colleagues can take care of a lot of these babies. We choose to consult on the most high-risk babies, especially the preterm intestinal failure babies as well as babies with ultrashort bowel syndrome, which is about 30 cm of small bowel, babies with gastroschisis with atresia that's complex. If they have a blockage, they not only have their intestines born outside of their body, but there's also a blockage and they'll need surgery. And then babies that are dependent on parenteral nutrition and are unable to tolerate enteral feedings. Sometimes we do get involved in lower-risk babies, but we try to focus on the high-risk babies.

And so, just some of our outcomes, some of these we've published, some of these we haven't. But if we're just looking at babies less than 60 cm, that's generally the standard definition for short-bowel syndrome, and there are varying definitions in the literature, some are dependent on parenteral nutrition, but I'm going to go with 60 cm small bowel here. We have a very high survival rate, about 96%. 97% of babies have resolution of liver disease. When babies are on parenteral nutrition for a while, they get cholestasis and it has a new fancy term called "intestinal failure-associated liver disease" or IFALD, and we use something called Omegaven, which is a brand name for a fish oil lipid emulsion, and ever since we started using that, I know we've been using it at least since 2009, probably a little bit earlier, and what that does is it protects the liver and allows us to literally rehab or give the intestines time to grow and adapt to accept enteral nutrition.

I would say most of our babies, this says 63% here, but they are able to be on full feeds before discharge, but we do have a good number of infants we have to send home on parenteral nutrition. Either they don't grow on full feeds, just physically their intestines are not able to tolerate enough feedings, and then we are taking care of quite a number of, I call them ultra-short bowel syndrome and it's been, I didn't coin the term, it's in the literature, but basically these babies have anywhere from 8 cm of bowel, small bowel, so this is from duodenum on or the ligament of Treitz and up to 30 cm. Years ago, we would say this isn't survivable. This baby's going to need an intestinal transplant, very, very grim prognosis, but now with Omegaven to protect the liver, the lipid emulsion, and our ways of intestinal rehab, we're able to get these babies, they might be on TPN a few years, but they survive. And in the NICU, we've had zero intestinal transplants, meaning we haven't had to send any babies out to one of the centers in the country that does intestinal transplant. And this is important because we'll get babies from all over transferred in and the parents are saying, well, when's my baby getting an intestinal transplant. And we, we say, oh no, no, we just need time. We're not saying your baby will never need it, but we've been able to develop a method to avoid intestinal transplants. And it was interesting, when I presented this data, I don't know, 5 or 6 years ago, 2 surgeons that do intestinal transplants, were very surprised. But there are 50% mortality with transplants or higher and that's at the 1-year and 5-year survival. So, we want to avoid that.

We did publish some of our outcomes related to how much bowel length the baby had after surgery and these are all-comers. Some of these are preterm babies, some of them aren't, but I talked about the less than 30 cm population, we have a small number here, this was a couple of years ago. But if you look down here, at days to full enteral autonomy, it is just the fancy term to say they got to full feeds. But days to full feeds

for these babies, okay, so anywhere from a year-and-a-half to 2-and-a-half years. That is a long time on parenteral nutrition once the baby goes home, but in our outpatient clinic, which our GI partners run, they are able to manage that. And so as long as we can avoid sepsis and line infections, we just tell the parents very early on that your baby has x amount of bowel length and so we think your baby's going to be on TPN or parenteral nutrition, IV nutrition, for x amount of time. Sometimes, a few years, and some parents are okay with that and some parents aren't. It is a lot of hard work at home. I've had a lot of feedback from parents, but it is doable.

And to kind of switch gears, that's kind of my experience and our experience at Texas Children's Hospital and where I'm coming from and then, let's take it a step further. To not just intestinal failure in any baby, a baby born on time, what about our preterm babies because these are the tough babies. A lot of times these babies have had NEC or perforations and if they fail having a peritoneal drain, they end up having an ostomy and then trying to feed a baby with an ostomy, basically their bowels aren't connected, for a long time, that's very challenging. But just like with everything with preterm babies, we want to feed them early and I'm going to tell you why in a minute. You're probably like why would you feed a baby that had NEC, that has a high ostomy, but there is some literature and some thought behind why.

First of all, the intestine, I'll show you a picture in a little bit, but the intestine grows and I know that's like okay, yes, it grows, but it triples from early prematurity up to term age. There's this entire period of time that we need to give for the intestine to grow, even if they've had surgery in the interim, even if they've had a bowel resection. And then we know that feeding babies decreases this risk of cholestasis with the new term IFALD, and then if you can feed them sooner, you're more likely to get your central line out and avoid sepsis. From my first talk, I think Dr. Stansfield and I, we've told you and proven to you why we should optimize the use of mother's own milk. We should always use that. The problem is it's not always available or sometimes these babies aren't fed for a long time and they're in the hospital a long time and mom has to go back to work, she doesn't have a lot of milk supply. So, what else do we feed a preterm baby that's had surgery that has intestinal failure?

And could we use donor milk? And you also heard from Dr. Stansfield about donor milk and we know that, definitely we worry about inadequate protein, but also some of the immune factors and enzymes are denatured through pasteurization and then what about formulas and I'll talk to you today about amino acid-based formulas or elemental formula.

One thing I didn't talk about in my earlier talk which I usually talk about is something called oral immune therapy or oral care with colostrum. How many of you are using this in your unit, where you've giving milk to the inside buccal mucosa? Great. So, this is something that's really taken off. There's a lot of data that, some of it's promising like decreased sepsis, decreased ventilator days. Some data has shown no difference, but one thing that we do know is that, if a mom is providing the early colostrum with drops of colostrum to be put in either side of the mouth to their baby, their milk supply goes up. And we've seen this in the cardiac ICU as well. Oral care, if anything, I mean, it has to help the baby, but we need someone to study the oral microbiome and intestinal microbiome and all of that. But we know it increases mother's milk supply. So, we will use oral care with colostrum in our surgical babies.

But what are our goals in feeding these intestinal failure babies that are born preterm? Intestinal adaptation, which I'll talk a little bit more about in a minute, but we also want to make sure they continue to get great nutrition and they have good growth. Part of this issue is that around the time they have surgery and if they have an ostomy where they disconnected the proximal small bowel into an ostomy, they have to grow until their bowels can be reconnected. The problem is that whole period of time is a key time for catch-up growth, as well as bone mineralization, calcium and phosphorus. It's not good for these babies to not grow. It's not good for them not to get all the micronutrients and calcium and phosphorus they need because they'll get rickets. And so, trying to balance all of that with their surgical condition. And our goal, too, is to offer oral feeds as soon as possible. Now, if the baby's 25 weeks when they have surgery, they're not going to orally feed. They're going to be orally feeding closer to 34 weeks postmenstrual age, but promoting oral feeds early so they don't get oral aversion. And then intestinal adaptation, a lot of this has been studied in the basic science world, but just knowing that the intestine can adapt, it can regain function. It may take a long time, but it can do that. Also, even the architecture of the intestine can change over time and so some of the thought behind early feeding, especially with mother's milk, is that you can, with all these great nutrients here in the picture on the right, start helping the intestine heal and grow and you can get lengthening of the villi as well as enterocyte proliferation. So, it's good to feed.

This is the figure I wanted to show you guys. To my knowledge, it'd be great to repeat this study in a larger, smaller population. This is just babies that had surgery. But just showing you intestinal length. This is here around 20-something weeks compared to 40 weeks. So, I always think about 100 as what preterm babies should have. Term babies should have closer to 300. Now, the caveat is babies with certain conditions, like atresia, gastroschisis, they overall just have shorter bowel lengths and we need to publish that data. But a lot of them—I don't know if it's the way the anatomy works during development and when it halts, it doesn't grow—but that is a challenge.

But, if a preterm baby has surgery and they have a large amount of small bowel removed, but they still have, I don't know, 10 or 20 cm of small bowel, as long as we can feed a little, it's going to grow and it should grow and then when the surgeons go back in to reconnect the bowel, we often see the length longer. And I will say, it's been a process working with our surgeons to just say, hey, when you're doing your surgery, can you please measure the bowel length because it makes a difference for intestinal failure rehabilitation. And our surgeons have been great about that. Also, we have them draw pictures of what the anatomy looks like at the time of surgery because anatomy matters, whether there's an ileocecal valve, sometimes there's little pieces of bowel that are disconnected initially so we really like pictures. So, they're kind to show those to us.

How about pasteurized donor milk? This is the big question. Do we use this in a postsurgical preterm baby? I mean, we use it in preterm babies. Why not? Well, it hasn't been well studied. I think it's going to be a little tricky to study, but someone needs to do it. We need to figure out a way to do this. It makes sense because we already give it to our babies less than 1,500 g, but there's not a lot of data. And that's why we're optimizing mom's milk. And then the other question came up, we talked about doing oral care with colostrum, what about giving oral care with donor milk? That has not been studied. I'm not proposing we do that, but some people have proposed that and are using that in their NICU. We need to study that as well.

But I think the main reason we want to use mom's milk for all the lists of components it has, but mainly some of these growth factors. It has natural growth factors which are really key to intestinal adaptation. Also, we choose to use amino acid-based formulas, elemental formulas. There are 3 companies, I think 4, that make these. It's basically, as you can see in this picture, I was trying to find a good picture of digestive protein, but this is amino acid-based formula here, just the building blocks. And we often will use that to either fortify a baby if they're kind of closer to term or if we don't have mom's milk and the reality is, and I hate to say this because I'm a huge proponent of breast milk and donor milk, but sometimes babies with intestinal failure, I don't. I'm just assuming why they have trouble digesting human milk, but sometimes they have some intolerance to human milk. And I don't know if it's a fat-related issue or they just can't digest intact protein, but sometimes we have no choice but to give elemental formula. But we usually will try many, many times with human milk first before just giving elemental formula. However, there was 1 study published showing intestinal adaptation with elemental formula.

Dr. Stansfield showed a different version of this figure. This is from one of our papers. This is meant for a preterm baby, but I adapted it to give as preterm babies with intestinal failure because, in my mind, this is a similar thought process. I kind of talked to you about the first decision, what are we going to feed babies, and I hope I convinced you mother's milk and then we're not sure about donor milk. We just don't have a lot of data. And then considering elemental formula, amino acid-based formula.

And then, depending on, in this high-risk, low-risk, there's no science to this chart. We took our experience and we basically agreed upon which babies we think are hard to feed and which babies we think are easier to feed or which babies we know will have trouble advancing on feeds. And so, it's not a scientific list. It's based on our experience. But the first list of questions that I ask when someone says, "You know, Amy, this baby had surgery, it's a preterm baby, has an ostomy, how should we refeed this baby or how should we start feeds?" And most of the time, for our preemies, unless it's an undiagnosed congenital bowel anomaly, it's usually in our unit NEC. And so, mainly surgical NEC. My question is how much bowel was removed, how much small bowel do we have remaining, knowing that 100 cm is about what we'd expect for a preterm baby until they're closer to term age. Do they have an ostomy? And then this is where the surgeons are important. Where's the ostomy? Do you think it's a jejunostomy, meaning it's higher up? Do you think the ileum's actually pretty long, so is it ileum closer to the jejunum or ileum closer to the ileocecal valve and it actually makes a difference in how babies absorb nutrition, how well feeds are tolerated. And sometimes we don't know and that's the worst. The surgeons are like, uh, we couldn't see much, we pulled up a bowel loop and it's small bowel. So, then we start feeding the baby and then we have to figure out the absorptive capacity, where do we think this is? Is it a high ostomy or low ostomy? And then what's the baby's birth weight and gestational age? So, if you could imagine, like our babies that are 24-, 25-weekers that are 500 or 600 g, we're going to feed them a little differently or be a little bit more conservative than babies closer to 34 weeks, for example.

And we do have a protocol. I'm going to break this down. We created this this past year. It's pretty close. You know, we had to all agree to this. I agree with it. I just think the problem is every baby is variable. It depends how they tolerate feeds. This is like a starting point for our neonatology colleagues in our unit to just kind of see where we would start and then how we would adapt from there. And again, we're studying this, but this is based on 12 years of our practice. But I'm going to focus here about anticipated severe feeding difficulties, so I would say a preterm baby fits that. It's very hard to feed them sometimes. And we tend to start a little bit slower than our normal feeding rates for preterm babies. We usually start at 20 mL/kg/d for a healthy preterm baby. For these babies, we start around 5 to 50 mL/kg/d and then here in advancement, if they have really severe feeding intolerance, we only advance a couple of times a week. If they're doing better, we advance every 2 to 3 days. We try to be consistent in how we feed, but as you can, see this chart has a bunch of ranges. But then the more challenging part is, well, what if they don't tolerate feeds? Then you've advanced feeds a certain amount, so you kind of stop there because they're not tolerating feeds. Then you need to back up and we generally go back to a volume that we know they were tolerating. If they tolerated 40/kg, but then when we went to 60 mL/kg/d of feeds and they failed, we back down to 40. We often, for preterm babies, we definitely give partial parenteral nutrition with enteral nutrition, mainly because it takes them a while to get to feedings and a lot of them are not successful to be on full enteral nutrition before their ostomy takedown, their second surgery to reconnect their intestines. And then, like I said, we'll consider elemental formula if we've tried breast milk multiple times and we're having some failure.

I'm not going to go into this, but bacterial overgrowth. We talked a lot about the microbiome today, but sometimes there's spaces or dysmotility in the bowel and then bad bacteria grow and overgrown and cause problems like intestinal dilation can cause extra gas and sometimes we have to treat that with oral Flagyl. Sometimes we get unlucky, our preemies get unlucky, and some babies create more adhesions than others and some babies may have obstructions and actually may need that dealt with before their next surgery. We almost always use bolus feedings because that's physiologic. There's animal data and clinical data to support that. We only do continuous feedings if a baby's having intolerance to bolus and the reason for bolus too is that, like I said, we want to optimize oral feeds. If we are feeding a baby every 3 hours bolus, it's easier to transition to oral feeds eventually. And even our 8 cm small bowel babies, our ultrashort bowel babies, we used to feed those babies all continuous and then we realized that these babies, although they only had 8 cm of bowel, they wanted to orally feed and so that's where we switched to bolus. Now, over the past 12 years, we've switched to every-3-hour feeds.

I'm running out of time, so I'm going to go through this, but then how do we fortify and, sorry, Dr. Stansfield went through some of this, but in my mind, for a preterm surgical unit postop, there are two types of fortifiers and then sometimes, if they're closer to term like 36 weeks postmenstrual age, we'll consider fortification with elemental formula. But the main thing for preterm infants that I want to emphasize with ostomies is we have a concern about absorption. They might be tolerating feeds and their output from their ostomy isn't that bad, but they have a very high risk of growth failure. Remember I told you, this is a critical window for catch-up growth and bone mineralization. So, we can try to get them to wean off our parenteral nutrition before their next surgery and their reconnection of their bowel, but it often fails.

And we looked at this. And this is mainly because of my question. I just, I really worry about growth failure and I'm very hesitant to try to get babies on full enteral feedings with an ostomy, especially preterm babies. And what we found is that most babies do fail, like they need some type of partial parenteral nutrition supplementation for growth until their reconnection surgery. And then, if you have a jejunostomy, which is the high ostomy, forget it. Like, they'll tolerate some feeds, but not many. Ileostomy, I think it depends where it's at. Now, colostomy, on the other hand, that's the colon, so usually those babies can get to full feeds. But again, do they fully absorb the nutrition and grow? And a lot of our strategies for fortification, again, are based on gestational age, birth weight, how old they are at the time of surgery and when you're trying to give this fortification and nutrition. We generally fortify at 80 mL/kg/d in a postsurgical baby. Now, remember, we're advancing slowly so it may be a few weeks on enteral nutrition before we try to fortify.

And we made up 80. 80 just seemed like a good number. Basically, 80 is good because if they tolerate fortified feeds at 80, then we have a little time for them to prove good growth before removing the central line. And then, I've talked about some of this. The other thing I wanted to bring up was mucous fistula refeeding. This is in practice at many places, but we've adopted it. Basically, if there's output from the upper intestine, the ostomy, you collect that and you give it back one-to-one distally to the bowel. That bowel distally is usually called a mucous fistula. We do have our protocol where we get imaging. Not all distal bowel or mucous fistulas can be fed, depending on what the surgery was like and so the thought to this is if you feed this extra fluid from the upper intestine to the lower intestine, the babies will absorb better nutrition and grow.

And then what about less than 1,000-g babies? I don't know. Maybe I'd say less than 750. What about these itty, bitty babies that get NEC, they have an ostomy, what do we do with them? And really, I think the difference is that we're just a lot slower to wean parenteral nutrition before their next surgery. Sometimes we'll try this, but I will tell you, if they are less than 750 g, 24 to 27 weeks, they are going to have trouble growing and they have a high risk of rickets, even with fortified feedings with their ostomy.

And part of what we do, we just follow our protocol that we have for babies less than 1,000 g, so our preterm babies. We treat our preterm surgical babies the same and so we do fortify with a donor human-milk derived fortifier. And generally, it's well tolerated. This is just because we feed a less than 1,000 g preterm baby this way, we've carried it over to the surgical neonate. There's not a lot of evidence of which fortifier you should use. And one of the other things I need to emphasize doing bolus feeds over continuous feeds, but also just as soon as you can introduce oral feeds, so babies are cueing, they're showing signs they want to feed, that's really around 33 weeks postmenstrual age, we'll try to start orally feeding. Maybe not the full volume at the feed, but at least half of it because what we found is, 12 to 15 years ago, if we did continuous feeds and never gave the baby an oral feed until they were a few months old and after their second surgery, those babies didn't want to orally feed. And then they would skip bottle feeding or breastfeeding and they would go directly to table foods or green beans and, which is okay, but we should not be causing oral aversion. We should be trying to help it.

Just to recap. I think the most important point for preterm babies that have had surgery, whether they have a jejunostomy, ileostomy, regardless of their anatomy, we just need to be very careful and monitor them for growth faltering. We want to see weight gain, length gain and head circumference gain. What we do is we track these babies on growth charts, their measurements very closely, and we want to make sure that their growth curve is at least going up. If it flattens or starts to fall, we know whatever nutrition we're giving the baby is not enough. That's when we would optimize giving parenteral nutrition and lipids. And I know I didn't talk about lipids, so forgive me for that, but I'm happy to take questions on that during the Q&A session. That's a separate talk in of itself, but, you know, and then again depending on the anatomy, some babies will feed okay; some won't. And then I really would love for us, you know, retrospective data is a starting point, but it'd be great to have a prospective study. We just need to figure out if we don't have mom's milk, should we be using donor milk for this population, surgical population, or can we, can we use elemental formula?

And then let's see, these are some of the babies, not surgical, I couldn't find some of my surgical babies that we followed up, but these are preemies that I would argue that this is the result of high protein nutrition and modern nutrition. The parents say, she's not the shortest in the class, she's midheight, but it's hard to find her clothes because she's tall and lean. And I think, for so many years, we've been worried about body composition or the height of our babies and so it's nice that I think we're all focusing more on protein and we need more longer studies to prove this statement that I'm saying, but a lot of the babies we've seen in follow-up tend to be leaner and that is what we think is the next direction, but we need further follow-up.

I'd like to thank my team and these are our guidelines. Again, what we tried to come up with. This is every system. The book is actually very thick now. I have the 32nd edition picture up here. We're in our 33rd year and the book's gotten thicker because it has more evidence, but to the best of our ability, we try to synthesize new evidence every 6 months and update it.

It's not perfect, but it's a way for us to kind of practice consistently and it's free to download. You do have to put your email and they'll give it to you, but you can also Google if you don't have time to take a picture, *BCM Neonatology Guidelines*, and it'll pop up on Google and you can click it and download them. And we have an entire section now on intestinal failure, as well as nutrition.

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