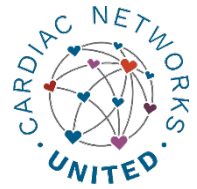


**November 10, 2020 CNU Fall Virtual Conference: Nutrition/Feeding
Q&A Submitted Through Chat Box**



(The panelists'/speakers' initials are noted in parentheses after each response)

- 1. For a baby in heart failure is an outpatient, if growth is suboptimal and parents are against having an NG tube, the patient is unable to drink adequate volumes of formula. What type of discussions do you have or recommend having with the family?**

This is a great question and a frequent encounter. I usually ask the parents why they are hesitant regarding the NGT. Many parents say, "I do not want to hinder the baby's ability to eat by mouth." Some report it as a failure towards an internal goal that "they will be one of the families that avoids the tube because they simply tried harder". Ask the parents to describe their perceptions of how the NGT will prohibit oral feeding. Many of our parents have the perception that the NGT will set up the baby up for failure to feed by mouth, which is simply not the case if a multidisciplinary team manages it. I say that the NGT is a "bridge" over a temporary hurdle. I redirect the conversation from the 'set back in oral feeding' to a conversation as to how important nutrition is for brain development. When I speak of brain development and nutrition, most families have never thought about it from that angle. At the earliest moments of introducing the concept of NGT, I in turn discuss the pathway to transitioning off the NGT as well. (KN)

- 2. Do you all have a guideline/protocol for placement of post pyloric tubes? All weighted tubes? Who places these tubes (Bedside RN, APP)?**

We do not have a guideline for post-pyloric tubes, but all tubes are weighted and the bedside RN typically places these tubes with confirmation both clinical maneuvers and abdominal X-ray. (DB)

- 3. In VAD patients, have you noticed any differences between feeding via NG or ND?**

We have not noticed a big difference between NG or ND in our VAD population. (DB)

We haven't in terms of renutrition. In general, we believe that intermittent feeding via NG is preferable to continuous ND feeds in order to stimulate hunger cues. (SH)

- 4. How long do you suggest an ng tube should be in place before deciding going to a g-tube? Often concerned how long the tube is in the pharynx and the UES.**

I don't have an exact timeline that I use. Previously, at our institution, we used to follow a general rule that if a child needed a nasogastric tube (NG) for longer than 3 months, we would begin to consider more permanent tube placement. Now, with improved education and support at our institution for patients/families being discharged on NG feeds, and some enteral tube weaning data studies showing some patients with NG tube may wean more quickly to oral feedings, than those on g-tube feedings, we are now open to keeping the NG tube in longer than 3 months, along with continually reassessing an infant or child's oral progress. I think there is no definite time frame that we say an infant/child needs to go from NG to g-tube, but we try to work closely with families, using a multidisciplinary approach, along with a nutritionist, social worker, and feeding therapist. We also collaborate closely with the patients' primary care teams, such as cardiology or neurology, to understand what other more global factors may be impacting that infant's or child's feeding advancement and see if we need to reassess more permanent g-tube placement. I am often less concerned of the NG tube itself causing issues in the pharynx and UES, unless it is: (1) inappropriately sized for the infant/child, (2) not in the right place, or (3) chronically being dislodged and replaced quite frequently. (MM)

- 5. What about a formula change? What formula progression do you typically use for those infants?**

We usually start out with Gentlease. We will advance calorie concentration on our neonates daily- 24kcal, 27 kcal. Those patients who are struggling to gain weight will advance to 30kcal. For patients who do not tolerate feeds (vomiting, diarrhea) we will change to hydrolyzed formulas (Nutramigen), then and consider elemental/amino acid based formulas (Elecare or Neocate) in extreme situations with blood in the stool etc. (LR)

6. How often are you diagnosing or presuming cow's milk protein allergy. For kids that are assumed CMPA and transitioned to appropriate formula are you at some point challenging that allergy by reintroducing breastmilk or cow's milk protein.

I consider the diagnosis of cow's milk protein allergy in any infant with blood in the stool, with no other known reason bleeding (i.e., no concerns for necrotizing enterocolitis or bowel ischemia), or an infant with recalcitrant emesis/gastroesophageal reflux disease, discomfort, or inability to gain weight, which is not improving with other interventions.

Yes, if it is a straight-forward infant milk protein allergy, with no concerns for having an IgE-mediated milk allergy, usually somewhere between 9-12 months, we will begin to trial reintroducing small amounts of milk protein into the infant's diet. We usually start with baked milk first and then if tolerated well, go to yogurt or cheese, and then eventually to whole milk. (MM)

7. I wanted to ask what your protocol is to initiating oral feeding post operatively. Do you require a certain level of compression via NGT prior? If patient is on O2, do they have to be weaned to a certain level?

We have a protocol in place where speech/OT see all of our neonates, and PO feeds are usually ok'd if on <2L O2. If they are worried about aspiration, they will send them for a swallow study. Patients who are at risk for vocal cord paralysis (HLHS stage one palliation, neck ECMO, arch repair, PDA ligation etc.) will all have a vocal cord evaluation (ENT scope or FEES). (LR)

8. My son tried a PPI and it didn't work. He takes Pepcid and that is a H2 blocker I think. What is the difference?

These are two different classes of antacids with slightly different mechanisms of action and potential side effects. Proton pump inhibitors stop the acid production of acid pump on the parietal cells of the stomach (parietal cells are the cells that secrete acid in the stomach). H2 blockers work on a histamine receptor on the parietal cell to decrease the amount of acid being produced. In general, proton pump inhibitors (or PPIs) are deemed to be a stronger acid blocker than H2 blockers. (MM)

9. I see a lot of CMPA diagnosis from GI physicians on the cards babies however after breastmilk is removed from diet and they are placed on an amino acid formula. The patients will still have the same symptoms as when on MBM and we lose MBM. I present this to the team in hopes to resume MBM but often Mom has stopped pumping. I believe this is due to poor perfusion from their cardiac defect rather than CMPA. How can you assess poor perfusion vs CMPA as these babies will have bloody stool and reflux etc.

This is a valid question with no clear answer, and I would agree that it's not a true milk-protein allergy since the national prevalence is much lower than what we see in our Cardiac population. We try to keep MBM as much as possible and occasionally have mom do a dairy-free diet if the bloody stools continue with a benign exam. We rarely change to non-milk based formula unless the stools have blood in them and other causes (NEC) have been ruled out. We have sent home very few patients on soy based etc. formulas. (LR)

10. Do you ever use anti-reflux formulas?

Absolutely! If someone can tolerate them, they can be very helpful. (MM)

11. Do you have a specific work-up prior to consideration of Nissen? e.g. Ph.probe/impedence, HRM?

In our institution, in general, we generally try to avoid fundoplication and trial a bridge with post-pyloric feeding if needed. In addition, there was a 2017 study which showed increase morbidity and mortality in congenital heart patients undergoing g-tube with fundoplication, so I do think, when performed, it needs to be thought about carefully. (MM)

12. Could you touch on the pros/cons of overnight continuous feeds?

Pros: the family does not need to wake up as frequently at night (q1-3hrs) to do bolus feeds; can usually pack more volume/calories in overnight as well. Typically well tolerated and can sometimes even promote better growth. Cons: the family still does have to get up q4h to refill the feeding bag; also the feeding tube can become dislodged (especially NG or TP) without family awareness. Patients could aspirate if vomit overnight. (LR)

The benefits of continuous overnight feeds I think is largely related to sufficient nutrition in the setting of post-pyloric feeds when on significant positive pressure ventilation. The only other benefit is not to the patient, but the caregiver of the patient, so that they don't have to wake up overnight for bolus feeds if they are indicated overnight. (DB)

13. Does anyone use gabapentin for feeding intolerances?

Gabapentin is a medication we will sometimes use, especially in older patients, who we think may have a visceral hypersensitivity component to their feeding difficulties or intolerance. (MM)

14. Do any of the panelists feel that we overfeed these infants or feed when they aren't ready? One question that always bother me is we have these standard protocols that shoot for target cal and with stopping and starting we may defeat the very purpose.

This is a question we discuss frequently at our center and I agree. Focusing only the kcal per kg we may miss important information the infant is driving. Is the infant gaining weight according to their own curve and what is the specific kcal each individual patient needs to grow on that curve (cardiac dietitian) and are we following the infant's cues with tube feeding (feeding therapist)? I was lucky to be trained by an insightful feeding therapist, Krisi Brackett, who taught observing how the infant tolerates all of their feeds (oral trials, tube feeding). She recommended taking the time to watch the beginning or end or entire tube feed to see if the infant is actually tolerating them or are we pushing the nutrition into them despite the infant telling us they can't tolerate it (Squirming, grunting, emesis after each tube feed, fussy at the end of feeds, GI symptoms-arching, multiple dry swallows, wet pharyngeal sounds). Gut comfort is integral to oral feeding acceptance. An important factor to be addressed during daily rounds is what is this specific infant's kcal needs, how are they tolerating it, how can we improve gut comfort /tolerance. Happy to discuss in more detail our approach specific to our center if interested. courtney.jones@imail.org. (CJ)

For VAD patients, we are always way behind on nutrition and only after more than a month or more on device might we get to the point where a patient is being overfed. In regards to feeding when they aren't ready, there is some truth to that when it comes to restoring adequate cardiac output to the splanchnic bed and initiation of feeds, but ultimately they need the calories to work on healing both related to their heart and their gut. The problem of starting and stopping feeds for these children is critical when the goal is nutrition repletion in the setting of heart failure and post-operatively after VAD. (DB)

15. It happens to us that post-operated cardiac patients with down syndrome present oral intolerance, which improves with continuous infusion, we do not use hydrolyzed formulas frequently, do you recommend using probiotics and gastrokinetics?

I don't know of any studies regarding the use of probiotics in post-cardiac patients with Down syndrome and feeding intolerance, and in general, I think we are still trying to figure out which probiotics, and under what circumstances, they may be the most helpful.

Depending on the reason for feeding intolerance, we sometimes will use prokinetics, such as erythromycin, successfully in patients with gastric feeding intolerance. Since some prokinetic agents may result in QT prolongation, we usually ask for cardiology approval if we think it may be useful in a patient. (MM)

16. The emergence of the child's skills are all different. What is a typical time frame for oral skills to declare themselves? This speaks to our Length of Stay and should we be letting them stay inpatient longer to practice with aggressive SLP help?

Love this question. All babies' skills are different and babies declare themselves at different stages dependent on the factors that disrupted their feeding development. I would not recommend increasing length of stay to work on feeding with SLP. From the earliest possible moments, an SLP should be making contact with the family to train them on the oral stimulation strategies, the feeding strategies and all the developmentally practices that we know will help babies feed with success. I focus my feeding sessions on caregiver education on reading the feeding cues. I always send the baby home with "something" they can do that is feeding related, even if it is just the pacifier dipped in breast milk. We have a process at Nemours where any baby who is sent home with an NGT or a modified feeding plan (ex. a restricted flow nipple, significant feeding support such as pacing or thickening) will be fast tracked into our Outpatient feeding program. We have a cardiac dedicated Outpatient SLP/dietician. We work on barriers to follow up even prior to discharge to establish a plan for getting developmental feeding support within a few days following discharge. (KN)

17. I love the focus on parental stress with feeding. This is a topic our facility has recently really started recognizing and working to change the provider's verbiage related to this concept. If you have any recommendations for resources in this area to share with multi-disciplinary staff, I would be really interested in how it was presented to be so successful in culture change at your facility.

Great question! The culture change at our center has taken time. I started by rounding with the CICU team daily for about one year until we became a regular fixture in the CICU providing next step feeding recommendations where we could suggest neuroprotective activities if the infant was not ready for oral feeds (skin-to-skin, oral readiness, oral cares with human milk, or calming with cares and procedures). The rounding transitioned to 1x weekly neurodevelopmental rounds and then increasing formal education through our heart center grand rounds which is mostly attended by physicians, APP's and CT surgeons. We have recently been asked to provide education to incoming nurses (basic), and intermediate and advance CV training related to neurodevelopment. It has been a slow transition to incorporating and accepting neuroprotective activities supporting long-term oral feedings. Here are some of the references that helped with education. (CJ)

- Butler SC, Huyler K, Kaza A, Rachwal C. Filling a significant gap in the cardiac ICU: implementation of individualised developmental care. *Cardiol Young*. 2017 Nov;27(9):1797-1806.
- Butler SC, Sadhwani A, Stopp C, Singer J, Wypij D, Dunbar-Masterson C, Ware J, Newburger JW. Neurodevelopmental assessment of infants with congenital heart disease in the early postoperative period. *Congenit Heart Dis*. 2019 Mar;14(2):236-245.
- Sood E, Karpyn A, Demianczyk AC, Ryan J, Delaplane EA, Neely T, Frazier AH, Kazak AE. Mothers and Fathers Experience Stress of Congenital Heart Disease Differently: Recommendations for Pediatric Critical Care. *Pediatr Crit Care Med*. 2018 Jul;19(7):626-634.
- Lisanti AJ. Parental stress and resilience in CHD: a new frontier for health disparities research. *Cardiol Young*. 2018 Sep;28(9):1142-1150. doi: 10.1017/S1047951118000963. Epub 2018 Jul 11. PMID: 29991369; PMCID: PMC6103210.

I have to say that it was our psychologist that have really mentored our staff over the years in parental stress, grief about loss of normal expectation of the infant. Parents do grieve the expectations and experiences that they wish they could have had surrounding feeding and feeding by far is one of our most emotionally driven topics. Our psychologist have regularly supported us with the verbiage to change our communication surrounding feeding and have worked closely slowly over time collaboratively to adjust our communication. Currently we have created a web-based training that our bedside RNS will take on how to speak about early feeding experiences. I would be happy to share via email if you wish Karli.Negrin@Nemours.org. (KN)

18. Any advice on how to navigate these waters when your facility does not have an inter/multi-disciplinary team? Often times the feeding therapist is trying to pull all the silos together which can be exhausting for the clinician and the family :) Or they're getting opposing opinions from different physicians.

I can completely relate to the frustration of not having a structured multidisciplinary team. I am a feeding therapist and our Feeding Clinic did not utilize hunger provocation with tube weaning. I presented the information from the literature review to our Feeding Clinic staff and provided a few of the articles about hunger-based tube weaning. They still didn't really seem interested until I weaned a moderately malnourished single ventricle pt. with the help of a dietitian and guidance from one of the other weaning programs (Seattle). I think the most important team members are the feeding therapist, dietitian, and medical provider. (NS)

19. It is interesting to know that for VAD patients post op you use higher requirements. Do you have specific equations for their requirements? We use average energy requirements, when stable on VAD sometimes adjusted for low physical activity, but do not use anything above average energy requirements for immediate post op period. Would appreciate knowing what you do!

I don't know the answer to this. I think it depends on a lot of things, like uni- vs. biventricular support, how much rehab they are doing, age, and other comorbidities. I've asked for more details from our nutritionist and will let you know! (SH)

20. What is the rationale your system used to determine using/encouraging standard formula if breast milk is not available vs. hydrolyzed? As a dietitian this is something I get considerable push back from my CVICU team on. They remain insistent on hydrolyzed formula even when it is not indicated.

Often the immediate post-operative management is being managed by our cardiology or cardiac surgery teams in our institution, so I would have to also ask for their input on this question. In general, I would think that a reasonable practice would be to start with a milk-protein containing formula or breastmilk first and using the more specialty formulas (partially hydrolyzed or completely hydrolyzed formulas) if there are medical indications for milk protein intolerance or colitis. (MM)

21. Do you always discharge to home? What about rehab or step-down unit?

Any patient who is on the hearts at home program-HLHS, single ventricles, complicated hospital course with ECMO, is discharged to home from the unit. Some neonates who require extended stays for social concerns or other mild reasons will go to the step down unit. We do not have a rehab service who admits- they only consult. (LR)

22. How does respiratory status for PGE-dependent neonates (apnea, hypopnea, tachypnea) impact preoperative PO feeding decision-making? Is there a uniform approach or provider/practice variation?

Our feeding protocol at Seattle Children's states respiratory parameters to allow oral feeds pre-op are support on less than 4L on nasal canula and respiratory rate below 70 /min. Beyond that, any bedside concern for respiratory distress at baseline or with feeds would consider holding feeds. We do not encourage tube feeding on higher respiratory support / ventilator support, but when possible, we use oral care with BM. Our guidelines also do not address apnea that is common in our infants on PGE, but while evaluating for apneic episodes, if there is risk of reintubation or escalation to CPAP support, feeds should be held. (ES)

23. During the VAD talk, there was some mention of increased requirements post VAD in the initial stabilising phase. What evidence is this based upon please, and are there any guidelines for this practice?

I don't remember saying much about this, but nutritional requirements are likely higher in the early post op period to facilitate surgical wound healing. (SH)

24. Currently our centre does not feed patients on prostin, or pre-Norwood SV infants. Would the professionals who discussed pre op feeding be happy to please share their evidence? Because I am very much hoping to look at changing our current practice.

I think the NPC-QIC nutrition algorithm is a helpful resource, specifically for the single ventricle population [Slicker J, et al. Nutrition Algorithms for Infants with Hypoplastic Left Heart Syndrome; Birth through the First Interstage Period. Congenit Heart Dis. 2013;8:89-102]. The algorithm recommends encouraging pre-op feeding when safe, breastmilk is preferred, and states that infants can be fed on PGE. As far as I know, there is no large study published, yet, proving the safety of pre-op feeding in relation to NEC. It is my opinion that with improved ICU monitoring, pre-op feeding of stable infant with bedside assessment by nursing and providers, can minimize the risk for NEC. (ES)

25. I attended the nutrition/feeding conference on Wednesday. What was of particular interest to me, as the parent of a Fontan kiddo, was how important nutrition was to avoiding or simply forstalling the likely eventual heart failure. The breakout session I attended was called something like Nutrition and Heart Failure. It was very informative, but on reflection I wasn't able to come up with anything other than "good nutrition is good" as a take-away for what I should do as a parent for my son. I am wondering if I missed something in the presentation that might have been more specifically aimed at parents. Do you happen to know if there were any recommendations coming out of that session for parents? I apologize if the answer is obvious as I had to watch the zoom while at work and sometimes I am distracted.

So glad you listened. The talk was really geared for health care providers taking care of children with heart failure (both with congenital heart disease and cardiomyopathy), and particularly those undergoing VAD implant as a bridge to transplantation.

For healthy Fontan patients, I did mention the propensity for obesity given the typical deficiency in achieving normal stature and the tendency to have an abnormal fat:muscle ratio. New data is emerging on the importance of exercise in these patients, which I would encourage as tolerated. (SH)

26. Do any of the institutions find value in utilizing Occupational Therapy for feeding in the cardiac population? OT and SLP seem to be a dream team for feeding when they work well together. Lactation is also been a great addition to the feeding team for support of skin-to-skin holding, in preparation for non-nutritive and nutritive breastfeeding.

I am an occupational therapist, so I definitely see the value 'in utilizing Occupational Therapy for feeding in the cardiac population'! :) Feeding and swallowing evaluation and treatment fall within the scopes of practice for OT, SLP, and PT. When we all work together, the patient and their family benefit. All three disciplines can bring their own special skills as long as they are competent in the more advanced practice area of feeding and swallowing. (NS)