

May 27, 2021 Webinar - Treatment of Feeding Disorders after the NICU: Changing the Paradigm

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Q and A

In regard to Rhett's tongue thrust, how do you differentiate knowing whether his thrust was reflexive versus volitional?

The tongue thrust reflex, or extrusion reflex, integrates between 4-6 months, about the time we are introducing purees. This is why you spend more time "shaving" the baby food off of their chin with a spoon and re-feeding them! The baby may open their mouths to receive the spoon but still use a suckle response... the same anterior-downward tongue pattern that they use when taking a bottle. It is typically more rhythmical and repetitive. With our friend Rhett, if the volume had been on, you would have heard him literally blowing raspberries to "spit out" by finger. His looked intentional and controlled and he had the facial expression (brow furrowing) of disgust with my gloved finger while doing it. The closest example that I could find on YouTube is at <https://www.youtube.com/watch?v=-ZXd3xLV8Dw>. It's not an ideal example for a variety of reasons, part of which is that at rest she already has an anterior posture which is not typical, but you do catch a glimpse of the repetitive thrust on that video. Around 6 months the infant starts to use their lips to actively compress to clean the bowl of the spoon and the tongue thrust is typically integrated at that point. It's always great to get video from or ask to observe friends with babies who are typically developing to get a solid idea of what to expect.

What would you recommend for those NICU graduates that do not want anything to do with a bottle?

I would recommend that you first find out why. There are a lot of reasons that a baby may reject the bottle. It is typically not a sensory integration deficit (though it could be) as much as it is a protective response to avoid what they know will be a noxious experience... survival of the fittest. The important question is to ask why. That will be the first step in knowing how to address it. If they have frequent emesis or severe reflux, all oral experience has been negative, and even the smell of their formula will begin to trigger refusal. Constipation is another huge factor... it holds us hostage from progressing oral feeding. Why would they want to eat if they already feel full or uncomfortable? Working with the pediatrician, dietician, or G.I. specialists can be very helpful, and resolving that alone may increase an infant's interest in the bottle. Working with the G.I. is also helpful if you notice any signs of a sensitivity to the formula or expressed breastmilk which may cause an infant to refuse. The feeding schedule may be prohibiting establishment of age-appropriate hunger-satiation cycles. I always work toward what is "normal and natural" and try to approximate the feeding schedule to what that baby would be doing if there was no significant medical history, and they were eating by mouth when and how much any other baby would. It's also important to know if there was any history of aspiration as the cause of the patient being a non-oral feeder. You may have to modify flow rate, temperature, position or viscosity if trials with liquids that were problematic are perpetuating refusal. A very thorough genetic screening and oral-peripheral exam is imperative to rule out any anatomical or neurological deficits that you would miss if you didn't complete that. So, the treatment approach will depend on the underlying cause. Once the issue or issues have been identified and resolved, then you can feel more confident about moving forward.

If the infant is under 8 months, I will still work on establishing non-nutritive with finger or pacifier, and nutritive sucking through bottle feeding. If they enjoy a pacifier, dipping that in EBM (expressed breastmilk) or formula can be helpful. I have used a medicine pacifier to deliver slow, controlled bolus

volume as they suck non-nutritively on that nipple, so they get droplets while they have already established stability on the nipple, which provides better bolus organization than a pacifier dip. Positive oral play is also important, trying always to work toward what is "normal and natural" which would change based on the infant's age. Gum massage, especially without even touching the tongue, is often pleasant for the infant and is often successful at gaining permission from the infant to be in their mouth. Once that trust is established you can move forward with crossing midline over the anterior third of the tongue, avoiding mid-blade which is much more invasive and noxious. Incorporate palatal stimulation, again, starting and remaining just at the alveolar ridge and moving laterally back and forth across midline. Once that is established as safe and pleasurable to the infant you can gradually work your way more posteriorly along the palate and the tongue, gradually getting to the point of eliciting that reflexive suck response, or hopefully encourage a volitional non-nutritive suck. As that advances, small volumes of liquid can be added in the way of pacifier dips or very small volumes in a slower flow nipple, gradually advancing flow rate as the patient accommodates. Always encourage oral play with their hands or teething toys... whatever is "normal and natural" for that patient's age. Establishing a safe and positive oral experience is crucial.

If the infant is over 8 months, I tend to focus more on a cup or straw. That is something I begin around 6 months anyway, but certainly after 8 months I personally have less success at transitioning to a bottle. On a side note, if you truly understand oral motor development, appropriate oral tone, and oral motor reflexes, you will be able to discern if oral motor "exercises" or "stretches" are appropriate for that infant. Often, unless there is significant neurological dysfunction already evident, they are not appropriate.

Was Ezra able to create the learned motor patterns since he didn't have them in the video? Lack of buccal contraction.

My beautiful little friend did not make it across that integration period. I am not his primary therapist, only consultative, but his primary therapist reported that he continues to have a predominant sleep state, has obstructive and central sleep apnea, and is a candidate for a tracheostomy. He has had a recent hospitalization for pneumonia and has apparently not had oral feeding for some time. The video that you saw was approximately a year old.

Are Ezra's cheeks a low tone indicator? I notice them sucking in more when compared to Rhett during bottle feeding.

Unfortunately, yes. Although he obviously still had lovely fatty pads in his cheeks, as did Rhett, which allowed him to sustain negative pressure for functional sucking with some support, the resting tone of his cheeks offered no resistance to the negative pressure created during active sucking.

How do you handle the situations when you find the parents continue their reliance on other caregivers (i.e. home nursing)?

That can be a very tough situation. First, we have to think about the baby, and ensure that they are getting what they need from us... do we have the correct treatment approach and plan of care (POC) in place, do we have a manageable home program in place, do we have relationships with the primary specialists involved in the patient's care, and do we have medical releases to communicate with all of them. If all that is in place, then focus on who is with the baby the most and ensure that they are well-educated in the plan of care and are implementing that. We are very good at what we do, but we can't

“fix” anything seeing the baby twice a week for 45-minute sessions! It does take a team, so utilize what and who you have.

There are a couple of ways we will pull the parents in. Right from the start you can say “part of my treatment approach is work with the parent and nurse to ensure that we are on the same page. If for any reason you can’t be there for every session, I will text you the progress for the day. It’s best that at the very least you can be present for the last 5 minutes or so of the session so that we can review.” We do text a quick summary to the parents after the session, especially if we see the patient at a family member’s home or at a daycare. It also helps to utilize a home program notebook, which is written about in the question below. The key is involving them without overwhelming them, and giving as much positive feedback as possible.

What is a good way to convey patient progress for the parent with depression/anxiety/PTSD even when their infant may not be able to decrease enteral feeding support at the time?

That is a delicate subject. Often, I will tell them the following: “The frustrating thing but also the wonderful thing about your baby’s diagnosis is that in most cases no one can say with 100% certainty what he/she will or will not be able to do. It’s hard to not have an answer to that, but that is also the silver lining. Then we don’t place any mental restrictions on what they may be able to do in the future, even though they are not where we would like them to be with feeding right now. We will continue to work with him/her together to keep moving forward. You will know your baby’s mouth as well as I do, in both structure and function, so together we can see when we have hit a plateau. That doesn’t mean that we give up on feeding, but it may mean that we spend more focused time on language and communication development while you continue a home program for feeding and oral development. He/she will be going to school eventually, and we want to ensure that his development in these early years will help him be successful in that environment. When you feel that there has been a change, or your PT/OT has seen a change in stability with growth, we can reassess and return to an increase in feeding therapy. If we don’t recognize when we need to shift focus because of a feeding plateau, then Medicaid will presume they can no longer progress and will reduce treatment frequency when we know there may be future progress as he/she grows and motor skills change. I will still spend at least one session a month, or part of the sessions to monitor for change, check your comfort level, and offer any suggestions based on where things are at or questions you may have.” I have not had a parent discontinue services. If you have looked at their whole child and have helped them appreciate global development and preparation for school years, they are usually in agreement; but that is a very tough conversation.

What items do you include in the binder for the home program for the parent? and how often to review or look at the communication binder?

Some of our therapists utilize a small spiral notebook as a communication log that stays in a central place and has the plan for the week in it so that it serves as a visual reminder to implement the home program and track the data for caregiver goals in the POC. The communication log is looked at every time, because we try to give them one thing to address between the first and second session of the week. It’s only one thing, and often it may be the same thing across several sessions. We are asking them to document just in a word or two (or a number or volume) so that it is not overwhelming or cumbersome. If you do a binder, then you could even create a spreadsheet chart or Word document chart tailored specifically to what you are asking them to do with feeding times pre-written in a chart form. Do whatever it takes to make it quick and easy so they will more likely be compliant, even keeping a pen

attached to the notebook. If you communicate regularly with your PT/OT (if you are an SLP) or whomever the alternate therapists are treating the patient, you can put dividers in for them as well if they are interested. It is a good idea to put a copy of your patient's goals as written in the POC in the front of the book so families remain aware and reminded of other goals they can be working on as well as periodically reviewing to discuss progress.

My hospital (NICU) has very poor post-NICU follow-up, how did/do you suggest improving the post-inpatient care referrals?

It is definitely more difficult if your hospital does not have a referral process for developmental follow-up clinics or to specific developmental pediatricians in your area. I have had to good fortune of working in that setting for 20 years in San Antonio, and I have maintained relationships with neonatologists, case managers, feeding therapists, and specialists. I am also fortunate that we do have a variety of clinics within which I am able to see patients over time on a monitoring basis. I strongly encourage that when you DO get a referral from the NICU that you have a medical release signed and communicate with the feeding therapists. It is also helpful to go with a patient when they have follow-up swallow studies to engage with the evaluating therapist. Our therapists will frequently send brief summaries to whatever specialists they will be seeing in an upcoming appointment via fax with follow-up phone call to ensure that it's been given to the MD or nurse practitioner to be read prior to the appointment. If you can establish and maintain relationships with all of the players, then they are more likely to refer to you or your agency for care.

If you are the hospital therapist and trying to improve where to refer your patients, the inverse is true. The hospital case managers will send the discharge paperwork when they refer, which includes feeding evaluations, a few progress notes, the swallow study results. I would speak with the case manager to find out where they are being referred and if you are covered from a HIPAA standpoint to reach out to that agency and have the treating therapist contact you to discuss the patient. In the home health setting, we have a release to contact all medical professionals, unless the parent restricts any information or facility. Having the case manager add to the referral paperwork to have the treating therapist contact you and providing a contact number would not violate HIPAA if the family has signed that document. Hopefully, the therapist will follow-up. If you are consistent in doing this, you will get a feel for who is reliable and skilled in your community. Sharing with your case managers what therapists or agencies are collaborative may guide their decision-making on where to send referrals. As long as the family has signed a release that they can fax to your facility, then you could be available to that therapist as often as they would need to ask questions.

What is the name of Dr. Arvedson's book?

Arvedson, Joan C., et al. *Pediatric Swallowing and Feeding: Assessment and Management*. Plural Publishing, 2020.

Co-authors are Linda Brodsky and Maureen A. Lefton-Greif. Here is a list of the texts that I still use, and learned so much from throughout my career, especially when first starting as an SLP.

Wolf, Lynn S., and Robin P. Glass. *Feeding and Swallowing Disorders in Infancy: Assessment and Management*. Hammill Institute on Disabilities, 2007.

Morris, Suzanne Evans, et al. *Pre-Feeding Skills: a Comprehensive Resource for Mealtime Development*. Pro-Ed, 2000.

Vergara, Elsie, and Rosemarie Bigsby. *Developmental and Therapeutic Interventions in the NICU*. Paul H. Brookes, 2004.

Newer texts:

Suiter, Debra M., and Memorie M. Gosa. *Assessing and Treating Dysphagia: a Lifespan Perspective*. Thieme, 2019.

Needelman, Howard, and Barbara J. Jackson. *Follow-Up for NICU Graduates: Promoting Positive Developmental and Behavioral Outcomes for At-Risk Infants*. Springer International Publishing, 2018.

How do you encourage past NICU patient families to try feeding if they went home with a g-tube if they are content with predictability and ease of tube feeding than effort of trying oral feeds?

Unless there is harm to the child, that is the parent's choice and not ours. If the parents have expressed that they do not wish to advance to oral feeding, we cannot force them to transition their child to oral feeding. If the patient has been referred to you for that purpose and the parent has made it clear that they are not interested in treatment for dysphagia, your job is to write up your evaluation with your findings and recommendations based on your findings, keeping consistent with our ethical obligation to do a thorough evaluation and make recommendations based on our professional judgement of the infant's dysphagia status, recommendations, and prognosis to the physician from whom they were referred. That being said, even though the referral may have been for feeding, evaluation of the whole child may have indicated the need for speech/language/communication services, which should also be recommended.

What are some great resources you can recommend for learning more about reflex integration? I'd love a recommendation for resources for motor education (book, journal, course, etc.) please.

All of the texts that I've referenced above are excellent resources for information on primitive reflexes and reflex integration. There are so many sites online that cover neurological development, including videos of infant cranial nerve examinations. Any courses you can take toward NDT certification are extremely helpful in learning about primitive reflexes, neural maturation in the aftermath of neurological insult, and the neuromotor consequences of that insult. NDT offers infant certification courses and they are just an excellent source of understanding and integrating motor development into your evaluation and treatment approach.

How do you support a parent who had a negative experience in the NICU. With little contact with therapist and the therapist pushed volume feeding. Now the transition home is difficult and understanding the need to continue feeding supports in the home?

That's a great question. I speak to my parents often about quality vs. quantity... how I would rather the baby take 5 ml in a beautiful, organized, rhythmical and pleasurable fashion than to take 5 oz that they

had to fight their way through, costing them much more (on several levels) than the nutrition that was actually received. If the infant has been forced through feedings, when they are less reflexive and more intentional, they could then have the control to refuse oral feedings. You can support the parent by discussing how they personally perceived the quality of the feeding... if the baby appeared to enjoy it, and if it was a comfortable, pleasurable feeding interaction for the parent, as well as the baby. Educate the parent to identify any signs of distress, discomfort, or refusal, so that they can identify what is a pleasurable response and what is not pleasurable. You can assist in that by speaking out loud while you are feeding in order to narrate your thoughts, for example, "He doesn't seem to feel very comfortable at this flow rate." "She appears to breathe heavier when she is positioned in semi-reclined." While it's important that the parent feeds also during a session to become proficient at the interventions that are successful with the baby, it's also beneficial to have the parent step back and observe the baby's overall demeanor, facial expressions, etc., so that they can appreciate the overall experience from taking a step back.

Can you discuss the role of fat pads and prematurity as it affects sucking patterns and stability?

This is a very interesting topic as I see varying information on presence, absence, or development of buccal pads after premature birth. Much of what I have read indicates that if they are premature these fat pads haven't developed and **won't** develop after a premature delivery. I've never found anything in the literature that supports these specific types of statements. On the contrary, buccal fat is one of the first areas of fat to develop which occurs between 14-16 weeks gestation and does so in a deep to superficial direction. The **size** of the fat lobules are established after 23 weeks gestation, but their size continues to increase up until the 29th week of gestation. In a 2010 article by Youself, et al., "**A review of the gross anatomy, functions, pathology, and clinical uses of the buccal fat pad,**" the authors state that "The fat pad is well developed in the premature fetus and is one of the earliest sites of well-developed fetal adipose deposition." In fact, an early study by Poissonnet and colleagues in 1993 stated that the "sensitive period" for fat lobule development is between 14-23 weeks of gestation. The presence or absence at 29 weeks isn't the only factor that contributes to function or quality; however, as there are changes in the fatty acid composition of the buccal fat during the third trimester, just as there is a significant increase in overall body fat in the third trimester. Current technology and advances in medical care allow us to save babies earlier and as you watch that progression you see that body fat in general increases over time. Theoretically, there is nothing to suggest that buccal fat would not continue to increase with nutrition and growth as does the rest of the adipose tissue throughout the infant's body, especially since it is the first location of differentiated adipose tissue. It is our responsibility to assess function in these infants who will have a variation of stability, resilience, tone, and skill across all gestational ages and all diagnosis. We evaluate and treat the patient and their function, not their diagnosis.

The purpose of buccal fat pads is to narrow the intra-oral space with the cheeks bulging inward, not just outwardly. The smaller the intra-oral space, the greater the capacity for generation of negative pressure with the least amount of effort as the intra-oral negative pressure increases with jaw excursion during sucking. The bulging pads help to stabilize the nipple at midline, keeping it supported in the central groove of the tongue. The tongue/jaw make up the floor of the mouth, the buccal pads bulging inward make up the lateral walls, and the palate serves as the roof, which is imperative in the patient's ability to generate negative pressure. Think of it as a channel that is created to approximate the shape/size of the nipple for maximum efficiency. The smaller the intra-oral space, the "less room for error" through uncontrolled movement (instability) of the nipple potentially disorganizing the overall sucking process.

In terms of therapeutic intervention, for me personally in my practical experience, utilization of cheek or jaw support has been more about stability than presence or absence of buccal pads. If you remember our friend Ezra, he had significantly lower tone than his counterpart, but still had very pronounced buccal pads despite it. It was a nice clear delineation between structure and function; the fatty pads were there with growth, but the generalized hypotonia limited their potential to do their job, especially as infants arrive at that time of integration of the buccal pads and have to rely on the buccinator activation and TMJ stability for function.

Poissonnet, C.M., et al. "Growth and Development of Human Adipose Tissue during Early Gestation." *Early Human Development*, vol. 8, no. 1, 1983, pp. 1–11., doi:10.1016/0378-3782(83)90028-2.

Tostevin, P. M., and H. Ellis. "The Buccal Pad of Fat: A Review." *Clinical Anatomy*, vol. 8, no. 6, 1995, pp. 403–406., doi:10.1002/ca.980080606.

Yousuf, Saad, et al. "A Review of the Gross Anatomy, Functions, Pathology, and Clinical Uses of the Buccal Fat Pad." *Surgical and Radiologic Anatomy*, vol. 32, no. 5, 2009, pp. 427–436., doi:10.1007/s00276-009-0596-6.

How do you help reduce the fatty pads (thinking of a micro preemie who is now 5 with fatty pads similar to an infant)? Takes some purees but no liquids, minimal vocal but smart and active.

Great question! I'm not sure I know the answer to that! I think you would need to consider overall body fat, generalized muscle tone, and whether or not there is a genetic component/inherited trait (phenotype). I would look intra-orally to see if this really is a buccal sucking pad which is narrowing the intra-oral space with an inward bulge. My thought would be that even though they are not "necessary" if his tone is within normal limits, I'm not sure how they would be limiting him either, particularly with liquids, which requires more oral control which would allow some probably benefit from a smaller intra-oral space... again, less room for error. I would look at lingual function both clinically and on his last MBSS to see if he has possibly over-compensated with buccinator activation (subsequently overdeveloping the musculature) for some lingual deficit that allows for premature spillage over the posterior tongue and places him at risk for aspiration. His refusal of liquids is likely an appropriate sensory response to negative experiences, and the atypical structures may give you information on what the underlying deficits may be.

I would love any supplemental information or knowledge that you may have about any or all of these questions to broaden my knowledge base! If you have further questions, don't hesitate to reach out via email at cathy.wood@pediatricfeedingsa.com. I may have a delay in responding but will do my best.