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An 8 month old baby. Such a great age. As I opened my patient's chart and noted her age, an image of a typically developing 8 month old baby surfaced...social, smiling, interactive, eye contact, loves cause and effect games, is attached to their caregivers, and peek-a-boo is a comedy show. When H's parents brought her into the radiology suite, I got a glimpse of stress, worry, tension and fatigue. My work was cut out for me.

As I gathered medical information about this baby in mom's arms, I took not only the verbal descriptions but the non-verbal information from this New Hampshire based family. I began to form my hypothesis. Typically, babies and children are referred for videofluoroscopic swallow studies when the medical provider is worried that they might be aspirating. While my role is to perform this study, analyze the swallow physiology and determine a safe diet for each patient, my real job is to determine what I need to be worried about with regards to feeding, swallowing and nutrition. I take a visual analysis of oral motor tone, strength and coordination, I look at developmental markers- are there neurological signs which are concerning to me upon visual inspection (e.g. tongue protrusion, poor head control if appropriate, lack of eye contact, lack of attachment to the parent)? Does the parent report match what I have read in the medical record? And.. in some circumstances, I might even pause the intake and call the physician to discuss if this study is even indicated.

I began with my clinical history- Is she choking on liquids or solids? What is her medical profile? Is she healthy or sick, as this will dictate how conservative or liberal I might think about the recommendations? What do I hypothesize about the trajectory of the study looking at the baby, the behavior and attention, the intensity of the family, and the information I can learn about the baby. She was coughing and choking with bottle feeding. She had reflux. She had wheezing, increased work of breathing and multiple pulmonary infections. She was taking nebulizers without improvement. This is always an important question to help delineate what might be underlying asthma and what might be aspiration masquerading as asthma. She had been referred to our Interdisciplinary Airway Clinic and was starting her medical exploration in my care in our radiology suite. Do I think she might be aspirating? Is this primarily reflux versus swallow dysfunction? If she is aspirating, then why? Is there an anatomical divot in her larynx (a type 1 laryngeal cleft), I asked myself? I had to ask more questions to guide my understanding of her symptomatology. When does the coughing occur I asked? Often if a baby has coughing only after feeding, I can begin to form a reflux hypothesis, whereas if a baby has coughing or congestion during the feeding, I can "feed" an aspiration hypothesis. H was coughing during the feeding. Okay- I placed a checkmark in the differentials list in my head for swallowing issues. If reflux was the only culprit I would've expected coughing following feedings. What about

development? Developmental milestones? Growth? All adequate per parent report. I was also looking at her facial muscle tone – no copious drooling, no open mouth posture, her interaction with mom- she seemed to engage appropriately from a social context. As I asked more questions, I continued to feed my hypothesis for a swallowing disorder. This was really beginning to funnel my hypothesis into a type 1 laryngeal cleft.

Her videofluoroscopic swallow study began. I see many children with swallowing dysfunction, who later find out they have an anatomical deficit in the larynx, a laryngeal cleft. I do not take the responsibility for performing video swallow studies lightly. While there is always a cost-benefit for exams which expose children to radiation, I am very thoughtful and conservative in obtaining only the information I need, in the order which I need it. I started with a thin liquid from her current bottle system, expecting to see deep penetration during the swallow, and full clearance of the bolus following the swallow. I was also wondering if the reflux might show incidentally. But, after the very first swallow, my hypothesis was dumped out the window, and I immediately had to rethink this baby. Why was she needing so many sucks to withdraw the liquid from the bottle? I knew that this was an atypical finding. A Level 2 nipple which was a medium flow rate, should be faster and support easier fluid withdrawal than a standard nipple. Does she have some motor tone issues? Does she simply not like the barium? I know at 8 months of age that the sucking pattern is now no longer reflexive and therefore the volitional component may be impacting her interest in engaging with the bottle. This was a possibility, however. Her swallow wasn't what I had anticipated. Her pharyngeal peristalsis was weak. She had penetration during the swallow and a lot of residue following the swallow. This was really quite atypical in the pediatric population with a normal neurological profile. Hmmm. What was going on with this baby? Was there an undiscovered neurological issue that is surfacing in her swallow? I had to multitask: processing this physiological information, thinking about what I needed to learn, and keeping the study going forward to obtain the information in a timely manner. 8 month olds are notorious for throwing a bottle and declaring completion of a feeding at any moment. I quickly changed the nipple of her bottle system. No improvement. I had hoped that a slower flow might help to reduce her swallow issues by reducing rate of bolus presentation to the pharynx and/or reducing bolus size. Nope. Not better. In fact, more tongue pumping, more unnecessary calorie burning, and more effort therefore potentially impacting her coordination of swallowing and respiration. This was not a baby with a laryngeal cleft. This was a baby with reduced muscle tone, strength and coordination impacting her swallow. This was very different than my hypothesis. Next. Always weighing the cost benefit of exposing this baby to more radiation versus getting the necessary information. I quickly made a viscosity and nipple switch and used my best 8-month old distraction strategies, and the baby started feeding again. I determined the safest combination. Now, to implement.

But wait... I needed more information. *Why* was her swallow characteristic of a neuro-diagnosis? I needed to ask more questions. I looked at dad again. Yes- his facial features seemed a bit atypical. Low muscle tone, actually, his body appeared low tone overall. This

is the point where I need to ask questions and read the response of the parents. This is the time where I really want to ask if this baby has ever seen a neurologist but jumping into this question is loaded with negative stigma and possibly negatively impacting my newly forming relationship with these parents. I needed them to trust me. I started asking more about the milestones, what did the pediatrician think? Were they ever sent to early intervention? As I asked more questions, the family seemed to be willing to talk. Oh, they said, there was this episode long ago, but it probably didn't relate. Hmm... this sounds like it's definitely a piece of information I wanted to understand. They described to me a rule-out seizure that their 10 day old baby, now 8 months, experienced. Stiffening of the arms, rolling back of the eyes, straightening of the torso. Oh yes, they remembered calling 911 (why was this not salient enough to be shared previously?), and when the EMTs arrived, they thought it was a seizure or reflux. They brought her to her local NH ER, where the team deemed it to "must've been a reflux episode" as EEG monitoring revealed no seizures. Now, I really needed to get back onto the EMR and figure out why no one had documented this piece of information before. This was really important. I explained that I wanted to figure out the best way to help her. To figure out the best way to manage her swallowing difficulties and the best way to keep her out of the hospital for pneumonias. They were in. They were with me. They saw that I had the best intentions for their baby. I deemed it appropriate to suggest the additional disciplines that would be helpful. ENT, GI and Pulmonary were all seeing her upstairs in clinic with myself. Parents were nodding in agreement. But I was wondering if a neurologist would help to rule out anything else that may help us provide the best care for her. There. I had done it. I waited for the response.... This could've gone either way.... And yes! They were interested. We walked together to clinic, and I added more checks to the differentials in my head.

Thickening liquids in pediatrics is multifactorial and requires consideration of chronological, medical and physiological factors. By thickening formula or milk or water, the liquid moves slower in the mouth and pharynx and offers more time for the child to coordinate swallowing and respiration. The challenges are plenty- if we need to thicken their bottles- what should we use? Should we be adding unnatural thickeners to a baby's bottle? If we use real foods such as baby rice cereal or oatmeal, this comes with the risk of premature exposure to these potential allergens, or this may create constipation, or if the granules of baby cereal clog the nipple, then the infant fatigues and either does not get enough nutrition or hydration or begins to develop an oral aversion to the bottle. Of course fatigue itself may result in coughing and choking. A further challenge in thickening liquids is the temperature which infants drink liquids at- many may be offered warmed up/body temperature or at room temperature. What does this do to the consistencies we are recommending? But at the end of the day, we are simply trying to keep our patients healthy and out of the hospital, so sometimes the need for thickening is our best option. While our radiological exam provided a specific viscosity for safe swallowing, implementing this in the real world is accompanied by many challenges. For this baby, I needed to balance attaining the right viscosity as too thick resulted in risk for aspiration given coordination of the oral musculature plus respiration. Too risky would be to add cereal to the bottle given potential of clogging the nipple and increasing effort for fluid

withdrawal, but providing a commercial thickener, such as Thickit was an unnatural source of ingredient intake that we hesitate to provide to our young pediatric population.

I approached my Airway Team colleagues to develop a plan together. Given my new found information, a neurology consultation was a must. They were appreciative that this piece of her medical history was revealed. Was this also reflux? Could this be EOE (Eosinophilic Esophagitis)? Why the wheezing? What did we know about her upper airway anatomy? Many questions were highlighted, and our team prioritized the needs. This is a team of physicians that I have been working with for years. We frequently negotiate needs from each of our disciplines and have over the years developed an understanding of the optimal priorities for differential diagnosis for our airway patients. There is respect, but also challenge that makes us a high performing team. So, when I began to offer suggestions for possible thickening agents, they listened to my specific objectives and we problem solved collaboratively. This baby needed a thickening agent. Adding rice cereal to the bottle comes with plenty of risks and parent ability to titrate the recommendations to attain the correct viscosity. This was not the baby who could tolerate extra effort required to suck the thicker formula from the bottle nipple. We would need to go out of the box.

Given my work with the MGH Thickening Committee, I had already engaged in an interdisciplinary discussion about using a formula called Enfamil AR for its off label-use to treat pharyngeal dysphagia. I hoped that my patient H in my care would be an appropriate candidate. I proposed this off label option. My colleagues agreed to its trial. Additional recommendations were provided to the family including referrals to neurology, and luckily, given my thickening recommendation, postponing this baby's trip to the OR until we had trialed this more conservative approach. My goal was simply to mitigate the risks of the OR and reduce invasive procedures by trying to manage symptomatology.

The next time I saw baby H, she was 10 months old. Just 8 weeks and many data points were obtained. It is not uncommon for providers to hold off on trips to the OR in a baby this young, if clinical recommendations may help improve the health of the baby. Neuro and ORL both recommended a trial of thickened feedings as the first step. If this worked, she could potentially defer or avoid "a trip to the OR." I know that anesthesia comes with risks, and often the team wanted a baby to be a bit healthier if possible from a pulmonary perspective prior to an OR exploration. So, the stakes were high. If thickened feedings were helpful, then her medical course would change.

This sweet and worried family showed up in radiology again with tears in their eyes. Thickened feedings did not help. They were back for a repeat study as her swallow was not any better. Coughing and choking persisted, despite their intervention. It was hard not to notice that parents were worried sick. The next steps based on neurology's recommendations were a sedated MRI and a triple procedure in the OR. I assessed the situation here and asked myself several questions before proceeding. Why was this baby back for a repeat swallow? How and why was the swallow getting worse? I needed more information. We talked about how mom was thickening, how she was preparing the

formula, and then my intuition told me to ask her to show me. Out of her diaper bag came Similac Spit Up formula. Ah hah! What was this formula imposter? Why not the Enfamil AR that we had recommended? WIC. WIC. WIC. What I learned and changed within that day was monumental for this family. They had been prescribed Enfamil AR for “off label use” for aspiration precautions. Our team knows that this is a reflux precaution formula, but we are using it for another etiology. When the referral went in, WIC changed the brand to Similac Spit Up as this was another “reflux formula.” Clinical experimentation revealed that this formula was actually a thin liquid when prepared, not a thickened liquid like Enfamil AR was. Without the discussions of the MGH Thickening Committee, and without my intuition telling me to investigate further, this baby may have received a sedated MRI and trip to the OR that week. In addition, this baby was about to receive more radiation for a repeat radiological exam to look at her possible “worsening” swallow function. The family had been thinking that we were treating the swallow issues. The family had been worried, scared and beside themselves that our treatment wasn’t working. Luckily this was not the case. I cancelled the VFSS. I brought her upstairs to clinic and the gastroenterologist, family and myself sat down and figured out how to order the Enfamil AR to actually treat the issue identified. She may one day need more medical intervention. But for that day, these frightened parents could take a breath, make a formula change, and see how their baby would respond. Neurology is going to follow up. Our Airway team is going to follow up. But for the moment, the family had their next steps laid out for them... and they did not involve general anesthesia.

SAMPLE QUESTIONS

Clinician-Patient/Family Relationship:

1. In your narrative you describe the parents of baby H with stress, worry, tension and fatigue. Later you state that the parents warmed up to you throughout the interview process and were "on board" with your line of questions and plan for additional workup. Can you describe a situation when you did not easily form a trusting relationship with the parents of a sick child, and how you navigated this to form a therapeutic relationship?

Clinical Knowledge and Decision Making:

1. There were 8 weeks that elapsed from when you saw baby H for the initial evaluation and then again in follow up. During this time, the patient was not receiving the recommended formula and therefore not getting the desired benefit of your initial intervention. Is distant follow-up a clinical risk? What steps do you take to ensure families are successful with ability to follow through on recommended treatments, and to make sure they were able to retain the education provided

during the initial session when so much information is provided in a busy clinic setting, from multiple providers, under stressful circumstances?

Teamwork and Collaboration:

1. Working in a multidisciplinary clinic is an incredible way to help patients with multiple medical needs in an effective and efficient manner. Can you describe a situation in which there was a disagreement between providers regarding diagnosis/ care plan/ next steps and how you navigated this conflict to act in the best interest of the patient?