CASE STUDIES in Pediatric Dysphagia

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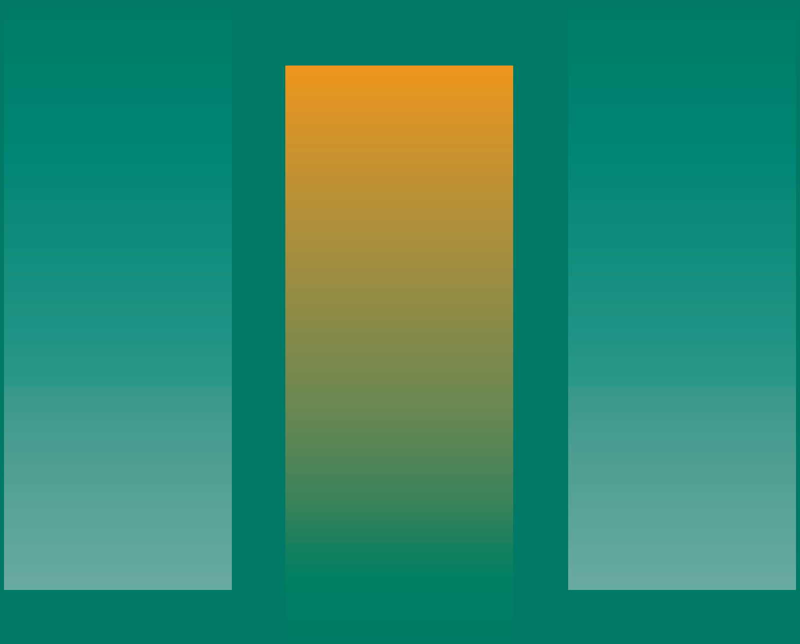

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CASE STUDY

The following case study provides an example of how multiple factors can affect feeding and swallowing progression. Jane was not only affected by extreme prematurity, poor prenatal care and maternal drug use were also part of her feeding and swallowing developmental challenges. She experienced further problems due to neuromuscular issues and pulmonary underdevelopment.

Discussion of her case followed by a conversation with a respiratory therapist will give the reader an appreciation for the respiratory challenges that many patients with pediatric dysphagia face.

Case Study Medical History

Jane was referred for outpatient feeding and swallowing therapy at 12 months of age. She had been seen through home health services for the past 3 to 4 months, with discharge reporting provided by physical and speech therapy. Prior to that, she received feeding and swallowing therapy through inpatient services while in the neonatal intensive care unit (NICU).

Jane was born at 26 weeks' gestation due to placental abruption. Some of the details were unavailable regarding prenatal care and birth since her birth parents relinquished their parental rights. Her adoptive mother will be the parent mentioned throughout this case when referring to Jane's mom. She began caring for Jane at 3 months of age.

Near birth, Jane presented with bilateral grade 3 brain bleeds and hydrocephalus. She remained in the NICU for 6 months after birth. At the time of her referral for outpatient feeding/swallowing therapy, Jane's mom reported the following medical information: She had multiple surgeries, including two shunt surgeries, G-tube placement, and patent ductus arteriosus (PDA) ligation. She has had multiple hospital stays, most recently due to a need for a shunt revision and a staphylococcal (staph) infection in her stomach.

Due to concerns for neurological and gastrointestinal functioning, medical tests performed included magnetic resonance imaging (MRI), computed tomography (CT), a gastric emptying study, a swallow study, an electroencephalogram (EEG), and a sleep study. A laryngoscope was scheduled for 2 months from the time of this 12-month feeding and swallowing evaluation. Current diagnoses were hydrocephalus, chronic lung disease, hypothyroidism, prematurity, seizures, and sleep apnea. She had a tracheostomy and began using a Passy Muir valve (PMV) 4 months prior to our evaluation. She required the use of a ventilator at night and when sick. See an image of a tracheostomy in Figure 6–3.

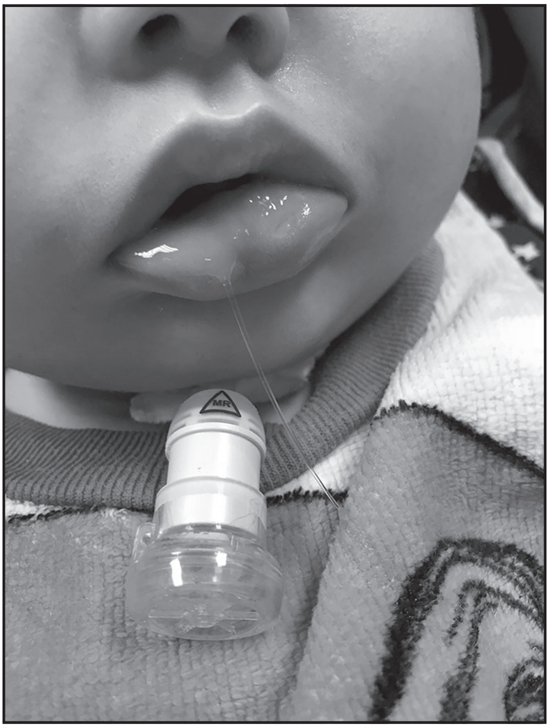

Figure 6–3. Tracheostomy.

Consider reasons and possible findings of her laryngoscope. What types of issues could occur 6 months after a tracheostomy? The respiratory therapist interviewed below will mention the importance of these findings in tracheostomy care and the decannulation process.

Mom also reported that Jane was teething, and it had affected her desire to eat and drink. She was reported to vomit when jostled right after a feed.

In the last few months, she had decreased seizure activity. Mom was hopeful that Jane would be weaned off seizure meds. Limited information was provided about vision and hearing during the initial evaluation.

Digging deeper: Discuss signs of seizure activity in nonverbal children with a neuromuscular disorder. What are some signs that suggest a child is having a seizure?

The providers (physical therapy and speech-language pathology) who were seeing Jane through home health from 6 to 14 months of age reported the following: "Progress with her rehab goals has been slow. She has been able to wean from mechanical ventilation throughout the day and only uses the ventilator when sleeping due to central apnea. She is now tolerating family and community outings and would benefit in transitioning to an outpatient setting."

What are some resources that would help the family with this transition? Who are some important professionals to have on the team to help with equipment and transportation needs?

Her speech-language pathologist reported that she "had a loose latch on the nipple and was able to extract liquid without signs of distress or aspiration accepting 1½ ounces at a time. She was able to tolerate the PMV."

She had an extensive medication list, including clonidine, Keppra, Synthroid, omeprazole, an iron supplement, Flovent, and MiraLAX.

Consider how the medications might affect her feeding and swallowing development. What were the purposes of the medications? Which medical specialists should be linked to which medications? See Jane's medical history timeline in Figure 6–4.

Jane's Case Study Timeline

- Outpatient referral for feeding/swallowing evaluation and treatment at 12 months unadjusted age
- Born at 26 weeks' gestation with complication of placental abruption
- 6 months in the NICU
- Limited history available prior to foster/adoptive placement
- Bilateral grade 3 brain bleeds, hydrocephalus near birth
- Placed in foster, and eventual adoptive care, at 3 months
- Current diagnoses: hydrocephalus, chronic lung disease, hypothyroidism, seizures, sleep apnea, global developmental delay, oropharyngeal dysphagia, gastroesophageal reflux

Figure 6–4. Jane's case study timeline.

Evaluation and Recommendations

During the evaluation, Jane was first presented with a slow-flow bottle nipple filled with 3 oz of formula given in a feeding position chosen by the mother that was typical during bottle feedings. She was positioned in an upright, supported posture with a slight distance from her mother near the edge of her lap. She demonstrated limited response to the bottle—specifically, there was no response through movement (e.g., kicking legs) or turning head toward the bottle. When it was presented orally, there was limited tightening/latching around the bottle nipple. Suck strength and coordination or non-nutritive suck were assessed using a gloved finger. Tongue movement was evident, but strength was decreased. Tongue cupping around the gloved finger was also decreased.

Facial grimacing was observed, and a slight head turn, away from the stimulus, suggesting aversion. Jane was also presented with formula on a small narrow, shallow bowl spoon. During feeding attempts, she exhibited slight facial grimacing and an inconsistent lingual response. For example, in one presentation, tongue pumping was observed with a 1- to 3-cc bolus presentation. Lack of lingual response was observed in another presentation.

Jane demonstrated limited motoric ability (e.g., volitional reaching, involuntary trunk support) and seemed to have difficulty attending to a visual stimulus. She demonstrated an expression change suggesting physiological stress upon being repositioned from the floor to the beanbag chair. She vocalized, smiled, and attended to her brothers and sister during a play routine (tickling, razzing her). Vocalizations were noted when she was using a PMV. The PMV was removed after approximately 15 to 20 minutes since Jane seemed to be experiencing more labored breathing.

There was no information at this point in treatment regarding a diagnosis of cortical vision impairment (CVI). This became evident during the evaluation, and we were able to work with a vision therapist through our early intervention system. Consider how treatment should be altered in response to information about CVI.

Though Jane was followed by a neurologist, she had also not been diagnosed with cerebral palsy. Jane's parents had been told that she would not be able to walk and talk due to her extensive neurological damage.

During this period, we began focusing on increased ability to express thin liquid from varied modalities, including a therapeutic open cup, increased positioning, and support to facilitate puree propulsion. Tongue propulsion was addressed through use of tools, positioning, and jaw/cheek support. Therapeutic focus continued to shift from quality versus quantity of intake and increased positive experiences with oral intake. Optimal mouth care was also addressed given that Jane was not eating daily by mouth. Jane was at risk for bacterial growth due to lack of oral use. There was also a concern that Jane would develop increased oral sensory hypersensitivity without passive and active oral motor stimulation.

Questions for the Family

Are there oral experiences that are enjoyable for Jane?

How often does Jane see the pulmonologist? What are his current recommendations?

What is Jane's current feeding tube delivery schedule and oral feeding schedule?

What are some ways that Jane currently participates in family meals or that you would like to see her participate in meals?

What types of instrumental testing and findings have you gotten regarding swallowing skills? (See areas of concern identified through the evaluation process in Figure 6–5.)

Respiratory Changes

Jane was diagnosed with COVID-19 and double pneumonia at 2 years, 6 months of age. She demonstrated increased pulmonary issues and began requiring supplemental oxygen. Initially, she was cared for at home but required intermittent hospitalizations over the next several months. Seizure activity also began increasing. Feeding and swallowing therapy was through telepractice. This transition was due to Jane's more fragile

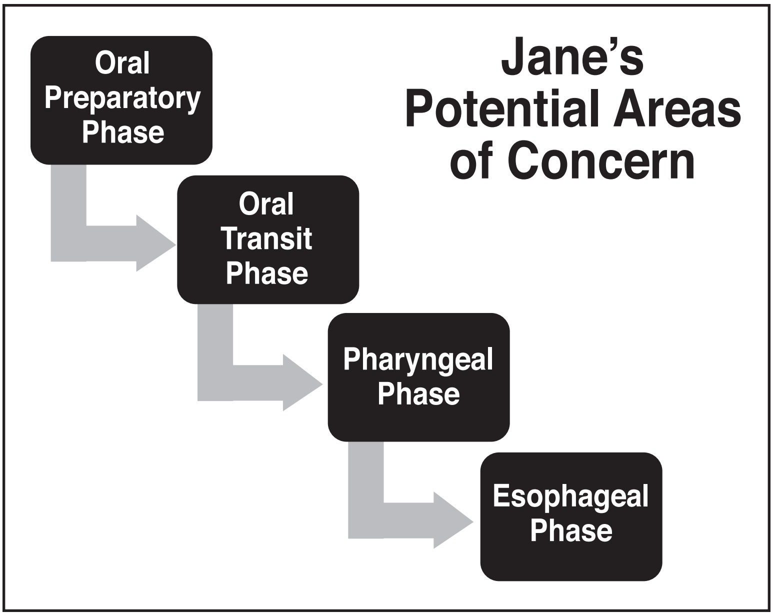

Figure 6–5. Jane's potential areas of concern.

system and the onset of a global pandemic. Some challenges at this point in treatment were changes in respiratory status, decreased access to adequate instrumental tools (e.g., less scheduling of modified barium swallow studies because of the global pandemic), and a challenging intervention platform given Jane's medical comorbidities.

Consider the best ways to support Jane during this episode of treatment (Marpole et al., 2020; Schwartz, 2021). When providing treatment to a medically fragile child, it is important to have up-to-date medical releases. This will give you permission to talk with their medical providers and share concerns.

Following the COVID-19 diagnosis, respiratory status was altered. Jane's parents were asked to report factors such as PMV use or capping, ventilator dependency during the day, and medication changes. Tremendous responsibility was placed on the parent and/or caregiver when working with a telepractice platform. Mom was guided to use therapeutic techniques. The telepractice platform served as a wonderful way of encouraging carryover of skills but was also a lot of responsibility for Jane's caregivers.

Pulmonary issues were not as evident using a virtual platform. Fortunately, the family was able to provide information about crackles, a need for supplemental oxygen, and seizure activity. Unfortunately, increased seizure activity and increased need for supplemental oxygen seemed to be hindering intervention during this period of Jane's treatment. Improvements were not happening as anticipated. Jane's mom reported that everyone else had recovered from COVID-19 but that's Jane's breathing difficulties were not resolved.

It became increasingly evident that the changes in her pulmonary status were affecting her skills in airway protection. Obtaining a modified barium swallow study would have been difficult at this point in the pandemic. Modified barium swallow studies can be helpful with respiratory changes. In the interview with respiratory therapist, Bob Yost, he will discuss cervical auscultation as a tool when respiratory changes occur.

During this therapeutic episode, Jane's mom was asked about the nutritional supplement that she was given through the feeding tube.

> Interviewer: What type of formula or blend is Jane receiving via G-tube?
>
> Jane's mom: We began giving her real food blends at 14 months of age. She did horrible with formula. She would throw up every feed. Her gastroenterologist talked about doing a Nissen fundoplication, but I asked if we could try blended food first.

A fundoplication is a surgical procedure in which the top part of the stomach is folded and sewn around the lower esophageal sphincter.

Three months after the COVID-19 diagnosis, more seizures were reported. Five months later, another seizure was reported, and she was diagnosed with streptococcus (strep). A significant seizure was again reported at 6 months requiring hospitalization. One year after the COVID-19 diagnosis, extra secretions were reported requiring emergency room care. Jane was placed back on a ventilator and moved to homebound status.

When respiratory concerns arise, it is important to consult a pulmonologist. In Jane's case, ordering instrumental measures was not an option at this point in treatment due to the pandemic. The pulmonary symptoms were increased crackles, increased need for supplemental oxygen, and increased occurrence of respiratory infections following COVID-19. Contacting the pulmonologist's office and sharing very specific information regarding observations can help patient management. For example, "Jane was observed to seem responsive today and mom reported hearing and feeling crackles throughout the day. Would you recommend any changes in her PO status?" See Figure 6–6 for further understanding of respiratory terminology.

Her mother was interviewed 6 months after Jane's COVID-19 diagnosis. Here is how she felt about Jane's feeding and swallowing skills at this point:

> Interviewer: Tell us a little about the journey that you have had with Jane in terms of feeding and swallowing and the challenges that you have faced.
>
> Jane's mother: Jane was born as a 26-week-old preemie and had suffered brain damage because of bleeding in her brain and immediately when they tried to feed her by bottle started aspirating the formula into her lungs. It became very evident early on that she would need a G-tube. When she was about 5 months old, they did surgery to put a G-tube into her stomach and that has been the primary way that she has been fed. She had a swallow study done, probably at about 8 months old or so, and she did pass it and they said that we could try to start offering her food and drinks. But because of her brain damage along with the fact that she had never had food, it has been hard

Medically Fragile Patients: Fitting Dysphagia Into the Bigger Clinical Picture
https://doi.org/10.1044/leader.FTR3.07182002.1

Treatment for Cough: Two Sides to the Story
https://pubs.asha.org/doi/10.1044/persp2.SIG3.113

Figure 6–6. Sharpening clinical skills in pulmonary diagnoses.