Progression toward oral feeding in a child with long gap EA: a case presentation of an interdisciplinary approach

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Introduction

Long gap esophageal atresia (EA) poses a challenge not only for the surgical and medical teams but to the non-medical teams. Aside from possible other malformations or syndromes, long gap EA signals an immediate and longer term consequence of an inability to feed, which interrupts maternal expectations of nurturing her infant. Repeated surgeries, hospitalizations, esophageal dilatations and multiple clinic visits and the keeping up with various medications tends to insidiously wear down maternal energies and slowly an inpatient desires to have the child eat and drink becomes the focus of maternal attention and energies.

Aim

We present a child with long-gap esophageal atresia (EA) to highlight the need of an interdisciplinary team to stabilize family expectations and establish full oral feeding.

Method

Currently there is no universally established guideline for the introduction of oral feeding as each centre follows their own protocols with respect to the development of oral feeding and drinking skills. In our case, both the nutritional and occupational therapist are involved early in the neonatal period to markuate oral motor skills in order to identify the method of feeding exclusive (oral, gavage or post-pyloric). When issues of appetite become apparent, or when mothers become weary of their child’s slow progress in obtaining 6-8 oral feeding, our feeding psychologist becomes involved.

Surgical, gastroenterologic, and nutritional interventions

Eva was born prematurely at 32 weeks GA, weighing 2 kg, with a suspected antenatal diagnosis of EA. A diagnosis of pure EA was confirmed after birth and a Stamm gastrostomy was placed on DOL #1. She received bolus gavage feeds of expressed breast milk (EBM) until the first stage Foker procedure was performed at 3.5 months. The distance between the two aortic ends was severe, with the distal esophageal pouch identified below the diaphragm. After serial mechanical traction of the esophageal segments, final primary anastomosis of the esophageal pouches was completed at 4 months of age.

After repair, Eva was fed by continuous jejunal feeds to treat severe reflux. She also continued to receive aggressive medical treatment for severe GERD. Video fluoroscopy was performed at 4 and 7 months of age to assess safety of oral intake. A high grade esophageal stricture (6 mm) was identified that required sequential endoscopic balloon dilatations (9 sessions) over a period of 10 months (5-15 months of age), to attain an esophageal diameter of 15 mm.

Over the same time period, Eva developed a cow’s milk protein allergy at 5 months. Initially, the mother followed an exclusion diet in order to continue with EBM. Eva’s weight gain was monitored and adjustments regarding the volume of formula feeds were made. By 12 months, bolus feeds were initiated via her gastrostomy (25 to 250 ml x 4/day). All the while, Eva demonstrated little interest in any form of oral feeding.

The EBM was changed at 15 months to Neocate Jr, at which time cyproheptadine was also started. Eva’s interest in food increased. Bolus feeds were subsequently increased to 50cc/10-15 min. Ongoing management of reflux was required and at 16 months esomeprazole replaced lansoprazole and ranitidine.

Conclusion

This case presentation highlights the importance of interdisciplinary cooperation and information sharing among professionals, so that appropriate steps can be made by the individual professional. The inclusion of the parents in the decision making process is a critical component of this process. Furthermore, family support for the parent became weary of Eva’s slow progress in obtaining oral feeding and Eva’s good developmental skills and her interest in tasting a variety of foods. Both the father and the grandmother were also involved with Eva’s care, and they supported the mother’s desire to have a plan towards full oral feeding.

After acknowledging the family’s frustration, a protocol towards full oral feeding was explained fully to the family, and this helped reduce maternal anxiety. The protocol stated that the patient could: 1. Safely feed orally 2. Accept a good variety of food in tiny amounts 3. Tolerate gastrostomy feedings of ~120ccs/30 minutes 4. Respond to cyproheptadine with increased appetite 5. Increase the quantity of food intake when gavage feedings were reduced by 25-50%.

Critical to the success of the protocol was the need for both parents and professionals to tolerate weight loss of <3% of body weight when gavage feedings were reduced.

Frequent visits followed until 19 months, when Eva finally tolerated gastrostomy feeds of 110ccsfeed and the nighttime continuous drip was slowly reduced. While Eva’s weight started to waver, the family remained determined to continue as she was reportedly really enjoying eating.

At 21 months, gavage wearing was terminated and careful monitoring of weight with full oral feeding continued. At 26 months, the much-awaited day arrived and the gastrostomy tube was removed.

Towards oral feeding: OT and the feeding psychologist

Neurodevelopmental assessment and oral motor skills were evaluated by the occupational therapist in the newborn period. Promotion of normal motor development was encouraged through proper positioning and early stimulation. As Eva grew, surveillance of developmental progression continued. Emphasis was focused on maintaining plausible stimulation in and around the mouth. Eva was encouraged to “feed” in the high chair at every family meal to foster sensory motor exploration, using food. Support was offered to the family in the event of difficulties or set-backs.

Eva’s mother’s first contact with the psychologist was when Eva was 8 months old. At that time, she was still feeding Eva with EBM via a jejunal tube, in addition to being vigilant about daytime and nighttime feeds to avoid vomiting. If Eva’s mother could not feed her child as she expected, she could, at least, give her EBM, despite the onerous process. By 8 months of age, the burden of care. Eva’s slow progress in obtaining oral feeding gave Eva’s good developmental skills and her interest in tasting a variety of foods. Both the father and the grandmother were also involved with Eva’s care, and they supported the mother’s desire to have a plan towards full oral feeding.

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