Oral Aversion in Complex Neonates: Is it Them or Us?

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The speaker has signed a disclosure form and indicated he has no significant financial interest or relationship with the companies or the manufacturer(s) of any commercial product and/or service that will be discussed as part of this presentation.

Session Summary

Complex neonates often develop feeding difficulties that prolong hospitalization and may complicate outcomes. In this talk we will review what a 25-year experience with CDH infants has taught us about minimizing or eliminating oral aversion and feeding difficulties in complex infants.

Session Objectives

At the conclusion of this activity, participants will be able to:

- list diseases which put a neonate at higher risk of feeding disorder;
- describe how the spectrum of disease of CDH relates to the risk of developing tube feeding dependence;
- discuss how instituting a feeding regiment that promotes the development of hunger in a tube fed infant increases the rate at which that infant transitions completely to oral feedings, and decreases the risk of developing oral aversion.

References


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Lessons learned from CDH

Disclosures

- I have no relevant financial arrangements or relationships to disclose
- The patients CDH work presented here was done at the University of Florida and at Johns Hopkins University at Johns Hopkins All Children’s Hospital
- All patients depicted have signed media consents

Oral Aversion:
The Magnitude of the Problem

- 3.5% of all newborns had feeding problems, 3-fold more if born < 37 wks, and 7-fold more if born VLBW
  - Motion et al. Ambulatory Child Health 2001
- Higher risk in many birth defects
  - EA/TEF
  - Facial
  - Intestinal defects
  - CDH**

What puts a child at risk?

- Any disease/disorder that moves normal oral nutrition to delivery by other forms:
  - Parenteral
  - Tube
    - NG/OG
    - Gastrostomy

Feeding Issues in CDH

- Spectrum of Disease
- Anatomy, Physiology, Treatment Required
Benefit from Delay of Repair (to decrease risk of ECMO)

CDH Spectrum of Severity (Left)

Small Bowel Colon Small Bowel Colon Stomach Spleen Small Bowel Colon Stomach Spleen +Liver +Liver

Benefit from Delay of Repair
(to decrease risk of ECMO)

Benefit from Early Repair
(to assure repair)

Kays, 2016

Spectrum of CDH related to Optimal Timing of Repair

Feeding Difficulties in CDH: Multi-factorial, **Patient Issues**

- “Bowel obstruction” in utero
  - Intestine, Stomach and liver in chest
  - Esophagus kinked
  - Inadequate swallowing in utero
  - Polyhydramnios (related to disease severity (L))
  - Foregut issues in CDH
- GERD
- Higher metabolic needs
  - Metabolic costs of small lungs
  - Tachypnea

Reactive Pulmonary Hypertension (resolves with time)

Fixed Pulmonary Hypertension (remains with lung growth)

Feeding Difficulties in CDH: Multi-factorial, **Treatment Issues**

Toxicities of Treatment

- Intubation: 2 – 6 weeks
- ECMO: 2 – 4 weeks
- Delayed PO feeds: Not until lungs are good

Feeding Difficulties in CDH: Multi-factorial, **Physician/Caregiver Issues**

- Assumptions that drive behavior
  - Nutrition is good
    - More nutrition is better
  - Better skills make for better eaters
    - Focus on taste, stimulation, mechanics of swallowing
  - Aspiration must be prevented at all costs
    - Patients that aspirate need g-tubes
  - Growth expectations
    - Should all neonates meet “normal” growth curves?
    - How much growth is “enough”?

Incidence of Gastrostomy, and Oral Aversion in CDH

- 40% had GER
- 33% had FTT
- 29% had G-tube
- 20% had Oral Aversion
- 19% had Anti-reflux surgery

- (meta-analysis of published studies of survivors)

Bagolan, Morini: Long Term F/U of CDH Survivors
Seminars in Pediatric Surgery, 2007

What are long term outcomes

- Unknown
- Many kids g-tube dependent for years
- Recently met one on g-tube for 9 years
- In our “Before” cohort, we had many kids on g-tube for 3 years or more
Treatment Concepts of the "Before" Cohort

• Is It Oral Motor or Sensory Related?
  – Focus on desensitization: Sensory issues
  – Focus on introduction of tastes
  – Focus on motor skills: learning to eat
  – Large focus on the "skills of eating"
  – Focus on social interactions with eating (later)
  – (what's missing?)

• Nutritional Goals
  – Maintaining "normal" growth, for the lungs and the brain
  – Since nutrition is good, more nutrition is better

Specifics

• OT/PT/Speech
• Assign feeds q3 hours
• Spend weeks working on feeds, while giving gavage for inadequate PO
• Advance feeds as needed to keep adequate weight gain (30 grams/day?)
• G-tube +/- Nissen for kids that don’t make it

After G-tube to Discharge

• Condense from continuous to bolus
• Assign feeds q 3 hours
• Offer PO, then give rest by g-tube
• Work to "normalize", i.e. transition from q3 hour feeds to q 4 hours feeds to 5 daytime feeds per day, etc.
• No feeding pump at discharge.
• Outpatient PT/OT/Speech

What happens?

• Kids with moderate PO intake often evolve to eating nothing
• Kids that ate nothing, continued to eat nothing
• Development of Disabling "oral aversion" (20% published)
• Why?
  – The next feed is too big and comes too soon.
  – They aren't hungry.
• Transition off G-tube was slow, 2 – 4 years, or more
• A few still on g-tube at > 4 years and longer

What's Next?
Oral Aversion Therapy

• Desensitization training
• Skill training
• Taste exposure
• Socialization plus eating

• Results were not satisfying

• So We Changed our Strategy
What's missing?

- What is the main reason that people eat?

Because we are HUNGRY

Back to Basics

- Babies are programmed to eat.
  - They know how to do it
  - But we need to let them get hungry
  - Maybe in our well-intentioned efforts to keep their nutrition and growth up, we are interfering with the basic development of hunger
- Supportive Actions
  - Getting tubes out sooner is probably good
  - Building oral-motor skills can be helpful in the right child
  - Non-nutritive sucking makes sense
- Hunger is central to the motivation to eat.

New strategy for feeding CDH (circa 2000) (unpublished, so far)

- Feeding issues in CDH relate to severity
- Less severe kids don’t have significant problems
- More severe kids, especially the left liver-up kids, ECMO kids, etc, have more issue
- Regardless, we introduce hunger early to drive more success

Optimizing Oral Feeding in CDH (and probably other complex kids too)

- Start with simple
  - Let the kids get hungry and see how they do
- If they don’t do well, initiate usual
  - PT/OT/ Speech
  - Decrease sensitization
  - Work on skills
  - Taste stimulation, etc
  - Let them get hungry

Feeding CDH kids

- Lungs come first.
- Feeds are a physiologic challenge
  - GERD
  - Lymphatic load
  - Chylothorax risk
- We don’t introduce enteral feeds until lung issues are resolving
  - Post-ECMO (rarely feed CDH kids enterally on ECMO)
  - Weaning from Vent

Some CDH kids will need Nissen/G-tube

- Current G-tube feed plan
- Start PO and by G-tube
- Advance both as tolerated
- Transition to “No Tube Feeds” during day (8 am – 10 pm)
- Give missed volume by continuous feeds at night (pump)
- Do it again the next day.
- Kids get hungry in the day and eat more
- Over time, PO feeds go up, Tube feeds go down.
- Simple, effective
Results

• Most kids PO and don't need a g-tube
• Left liver-up and more severe right CDH get g-tube/Nissen
  - No oral aversion
  - Eating full enteral feeds (off G-tube) by 4 – 8 months (95%)
  - G-tube out by 8 months – 10 months
  - Only most highly severe still on g-tube feeds at 1 year
    - (i.e. one pt. with 12% predicted lung volume)

Results

• Same kids, different outcomes

Literature Support

• Clinical Tube Weaning Support by Hunger Provocation in Fully Tube Fed Children
  - Hartdorff et al JPGN, April 2015

• Interdisciplinary Strategies for Treating Oral Aversions In Children
    - Motor skill building
    - Behavioral modification
    - Sensory Integration
    - HUNGER Provocation

Ongoing Questions

• What is “enough” nutrition?
• What is acceptable growth?
• At what level of lowered nutrition are calories limiting brain and lung growth?
  - Is this even an issue?
• Is it “fair” to plot severe CDH kids on a “normal” growth curve

Conclusions

• CDH infants are at high risk for feeding disability
  - FTT
  - GERD
  - Oral Aversion
• A feeding protocol that focuses on development of hunger, in addition to standard supportive measures, appears superior in minimizing oral aversion and g-tube dependence, compared to one which does not.
• Concepts elucidated in this population are likely transferable to other populations also at high risk for developing g-tube dependence.