The Heart of the Matter

Feeding Challenges in Infants with Congenital Heart Defects

Jennifer Fogel, M.S.CCC-SLP/L
*Employed by Advocate Children’s Hospital, Oak Lawn IL

*No further relevant financial or non-financial relationships to disclose

Oral Feeding Progression for the Newborn with CHD.........where to begin
Feeding is a journey not a destination

Building Experiences

State Regulation/ Oral Sensory Motor

Researching the Pre-Operative Period

- Poor Placental Health and poor weight association
- Full term more like pre-term infant.
- Evidence of Periventricular Leukomalacia (PVL) at birth

Matthiesen 2016, Licht 2002
### Prenatal Opportunity

- **Fetal Echo**
- **Support Groups**
- **Visiting**

**Feeding Method**

**Information**

Medoff-Cooper 2016

### Neuroprotection Care

- Low Stimulation (touch, sound, visual, oral motor during oral care)
- Milk swabs using to stimulation the tongue
- Tiny pacifier if sucking on tube
- Containment and protection during noxious medical procedures (diaper change to suctioning)

Butler 2017, Lisanti 2019, Miller 2020

### Neurodevelopment Care

- Finding opportunities to provide neurodevelopment care
- Providing cluster care during nursing assessment
- Education to parents
- Working together for parent involvement

Butler 2017, Lisanti 2019, Miller 2020

### Defects

#### Acyanotic Defects
- Arterial septal defect
- Arterial Septal Defect
- Pulmonary Stenosis
- Patent Ductus Arteriosus
- Aortic Stenosis
- Coarctation of the Aorta
- Ventricular Septal Defect

#### Cyanotic Defects
- Hypoplastic Left Heart Syndrome
- Total Anomalous Pulmonary Venous Return
- Transposition of the Great arteries
- Tetrology of Fallot
- Pulmonary Atresia
- Truncus Arteriosus
- Tricuspid Valve Abnormalities
Neurons that fire together....

Neuroprotection Before, During, and After Medical Intervention

Challenges with Equipment

- Lines/IV
- Intubation Tubes
- Respiratory Equipment
- Pumps
- ECMO
- Monitors

Butler 2017, Lisanti 2019, Miller 2020

Do you have strategies to help make it work safely?

“The mom already held the baby today....I have to go feed my other patient”

Individual Care
Family Centered Care

Butler 2017, Lisanti 2019, Miller 2020
Hemodynamic Stability

- When are they too sick?
- Lactate
- Blood Pressure
- Heart Rate
- Respiratory Rate
- Sepsis
- Too sick for nursing assessment?????

Pre-Operative Experiences

- Holding in parent arms
- Trophic Feedings (Prostaglandin) (NEC)
- Baseline tachypnea
- Umbilical Lines
- Days to Surgery

Post Operative Experiences

- Respiratory Support (intubation, NIV NVAV, HFNC, O2)
- Nutrition (Feeding Tolerance)
- Sedation & Pain
- Agitation (Calming Strategies)
- Medical Touch vs. Loving Touch
- Family Involvement

Standing Orders

- Standing orders for PT/OT/ST pre and post operative
- Physical Therapy -positioning, promote flexion and strength
- Occupational Therapy - State regulation and strengthening
- Speech Therapy- Communication, Cognition, Pre-Feeding Skills

Jones 2020, Leder 2016
Team Work

- Daily Morning Developmental Huddles
- Bedside Rounds Development & Feeding/Nutrition
- Multidisciplinary Rounds (PT/OT/ST/Nursing/APN/Physician/SW/Discharge Planning, Psych)
Oral Feeding Assessment

- Patient intubated
- Patient NIV NAVA or HFNC
- Patient Cares
- Pacifier Dips (Sterile Water/ Breast milk)
- Small Amount with Ultra Preemie Nipple 3-5 mL
- Completed with parent if possible

Considerations for oral trials

- Observe State Regulation
- Consider the reason for respiratory support
- Discuss if respiratory support can be adjusted for oral trials (ie. 5 liters HF possible to go to 2 for feeding)
- Discuss patient’s baseline vitals (HLHS 75-85 O2 normal range)

Considerations for oral trials

- Flow rate slow (slow flow, Ultra Preemie or Preemie)
- Position- side lying
- Hold the bottle lateral
- External Pacing for breathing
- Determine safe volume and frequency
- Education to nurses and parents for plan
Left Vocal Cord Paresis High Incidence In Aortic Arch Repair such as, TGA & HLHS

Pourmoghdam 2017

Feeding Recommendations

- Feed right side down for possible left vocal cord paresis prior to the swallow study (both sides)
- Limit volume to 5 mL...2-3 times per day
- If high risk for pneumonia consider pacifier dips
- Thickening not always advised for certain defects or poor strength and endurance

Feeding Plan Of Care

Coughing
Gagging
Refusal to begin
Head Turning
Color Changes
Hiccups/ Sneezing
Respiratory Changes
Watery Eyes
Sleepiness
Emesis or Vomitting

“Three Strikes You’re Out”

Three Strikes and YOU’RE OUT!
Feeding Plan of Care

- Provides “positive experiences”
- Measurable volume and frequency to avoid aversion
- With parent if possible
- Teach Back Important
- Coordinate with dietitian for improved communication of plan for parent
- Update frequently

Sample Goals

- SLP will provide oral sensory stimulation to promote pre-feeding skills with infant during intubation
- SLP will provide neuroprotective supports during medical interventions to improve coping and state regulation responses for improved pre-feeding skills
- SLP will provide education to parents and medical staff to implementation and benefits of gentle oral sensory stimulation for promotion of pre feeding skills
- SLP will develop an individualized plan of care to support pre feeding skills, neuroprotective care during medical interventions, and low stimulation neurodevelopment activities for infant in the PICU
- Make measurable based on assessment and experiences

Tube Weaning Plan

- Next priority of parent
- Coordinate with team most important-dietician
- Emotional support
- Pediatrician/Cardiologist
- Outpatient Feeding Services

Cardiac Newborn Neuroprotective Network

- Google Group
- Special Interest Group of CNOC
- Twitter @NewbornCardiac
- Facebook
  - jennifer.fogel@ah.org
  - samantha.butler@childrens.harvard.edu
Thank You!

National Collaboratives

- Cardiac Neurodevelopment Outcomes Collaborative (CNOC) cardiacneuro.org
- National Pediatric Cardiology Quality Improvement Collaborative (NPCQIC)
- Congenital Heart Academy You Tube
- Cardiac Networks United

Parent Support Groups

- Mended Hearts
- Conquering CHD
- Sister By Heart (HLHS)
- Hospital Programs


Coker-Bolt P., Jarrad C, Woodard F, Mertii P. The effects of oral motor stimulation on feeding behaviors of infants born with univentricular anatomy. April 2012 28(1)


