

The Heart of the Matter



Feeding Challenges in Infants with Congenital Heart Defects

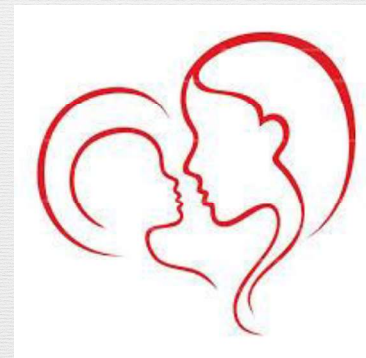
Jennifer Fogel, M.S.CCC-SLP/L

*Employed by Advocate Children's Hospital, Oak Lawn IL

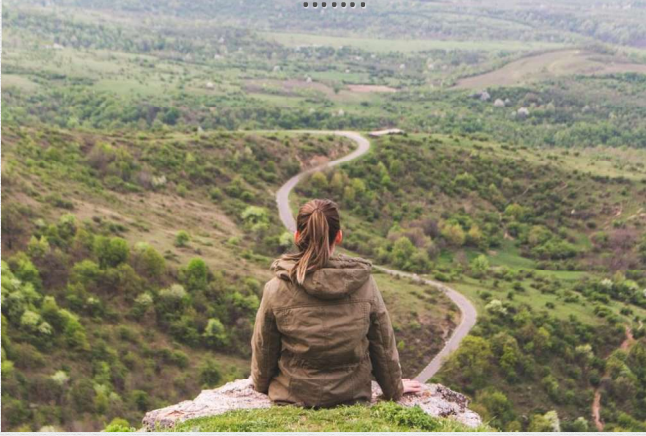
*No further relevant financial or non-financial relationships to disclose

A graphic for World Heart Day. It features a grid of 100 small hearts on a red background. One heart in the second row, second column is white, representing 1 in 100. To the right of the grid, the text reads: "1 in 100 babies are born with a CONGENITAL HEART DEFECT". Below this text is the hashtag "#WorldHeartDay". At the bottom right is the logo for the "CHILDREN'S HEART SURGERY FUND", which consists of a white heart outline.

Oral Feeding Progression for the Newborn with CHD.....where to begin



Feeding is a journey not a destination



Building Experiences

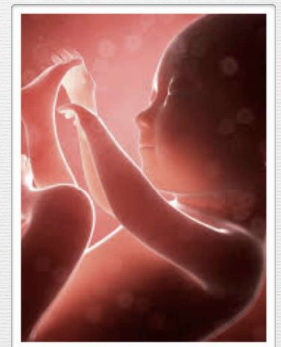


Building Experiences State Regulation/ Oral Sensory Motor



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

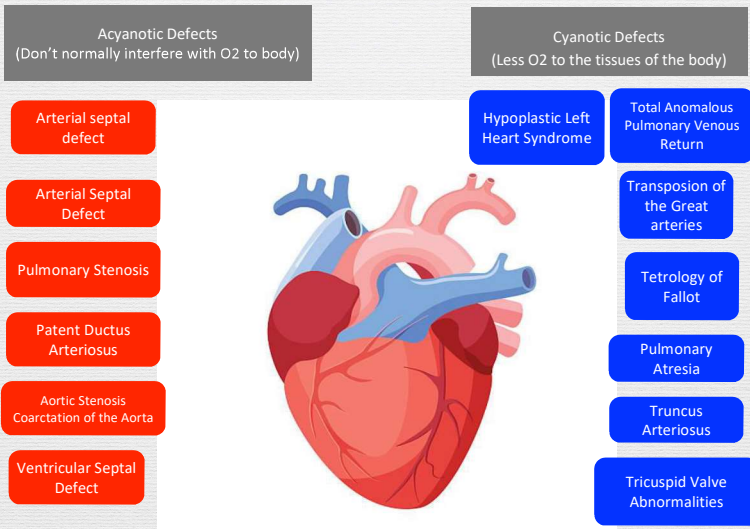


Matthiesen 2016, Licht 2002

Prenatal Opportunity



Medoff-Cooper 2016



Neuroprotective 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

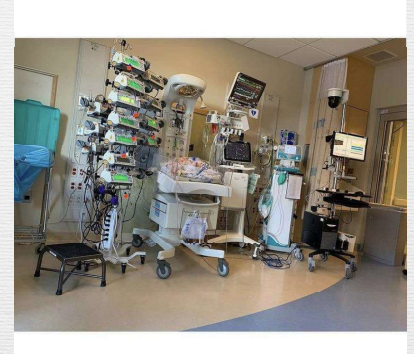
Neurons that fire together....



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 “



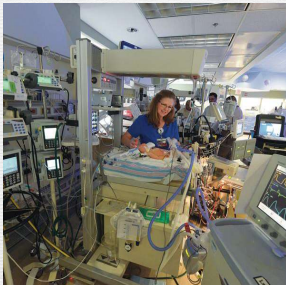
Individual Care

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

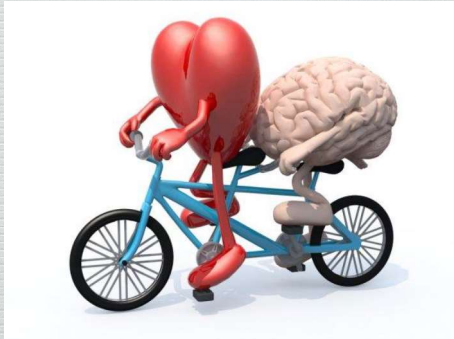
Post Operative Experiences

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

Jones 2020, Leder 2016

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



Brain + Heart = Human

It all goes together!



How does your team work together?

Everyone has a part? Or.....What are you talking about?

Team Work

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

Developmental Care in North American Pediatric Cardiac Intensive Care Units

Survey of Current Practices

Erica Sood, PhD; Wilma M. Berends, MSN; Jennifer L. Butcher, PhD; Amy J. Lisanti, PhD, RN; Barbara Medoff-Cooper, PhD, RN, FAAN; Jayne Singer, PhD; Elizabeth Willen, PhD; Samantha Butler, PhD

ABSTRACT
Background: Developmental care practices across pediatric cardiac intensive care units (CICUs) have not previously been described.
Purpose: To characterize current developmental care practices in North American CICUs.
Methods: A 47-item online survey of developmental care practices was developed and sent to 35 dedicated pediatric CICUs. Staff members who were knowledgeable about developmental care practices in the ICU completed the survey.
Findings/Results: Completed surveys were received from 28 CICUs (80% response rate). Eighty-nine percent reported targeted efforts to promote developmental care, but only 50% and 43% reported having a developmental care committee and holding developmental rounds, respectively. Many CICUs provide darkness for sleep (86%) and indirect lighting for alertness (71%), but fewer provide low levels of sound (43%), television restrictions (43%), or designated quiet times (21%). Attempts to cluster care (62%) and support self-soothing during difficult procedures (86%) were commonly reported, but parental involvement in these activities is not consistently encouraged. All CICUs engage in infant holding, but practices vary on the basis of medical status and only 46% have formal holding policies.
Implications for Practice: Implementation of developmental care in the CICU requires a well-planned process to ensure successful adoption of practice changes, beginning with a strong commitment from leadership and a focus on staff education, family support, value of parents as the primary caregivers, and policies to increase consistency of practice.
Implications for Research: Future studies should examine the short- and long-term effects of developmental care practices on infants born with congenital heart disease and cared for in a pediatric CICU.
Key Words: cardiac intensive care, cardiac nursing, child development, congenital heart defects, developmental care, postnatal development

Individualized Family-Centered Developmental Care An Essential Model to Address the Unique Needs of Infants With Congenital Heart Disease

Amy Jo Lisanti, PhD, RN, CCNS, CCRN-K; Dorothy Vittner, PhD, RN;
Barbara Medoff-Cooper, PhD, RN; Jennifer Fogel, M.S.CCC-SLP/L;
Gil Wernovsky, MD; Samantha Butler, PhD

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

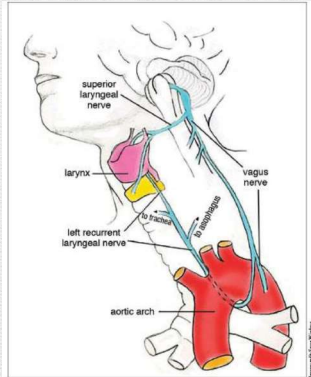
- Observe State Regulation
- Consider the reason for respiratory support
- Discuss if respiratory support can be adjusted for oral trials (ie. 5 liters HF possible to go to 2 for feeding)
- Discuss patient's baseline vitals (HLHS 75-85 O2 normal range)

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



Pourmoghadam 2017

Feeding Recommendations

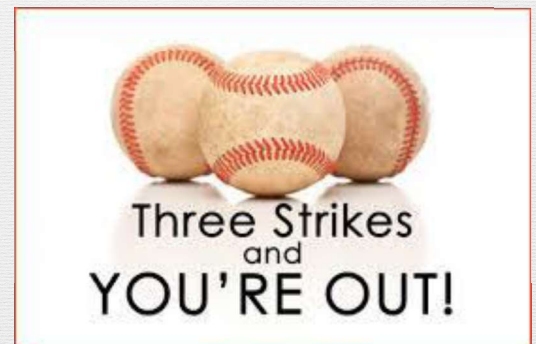
- Feed right side down for possible left vocal cord paresis prior to the swallow study (both sides)
- Limit volume to 5 mL.....2-3 times per day
- If high risk for pneumonia consider pacifier dips
- Thickening not always advised for certain defects or poor strength and endurance

Feeding Plan Of Care



“Three Strikes You’re Out”

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



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 PCICU
- Make measurable based on assessment and experiences



Desai 2019, Coker-Bolt 2012, Imms 2001

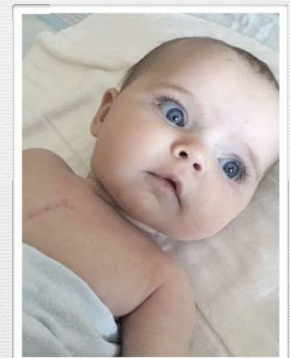
Tube Weaning Plan

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



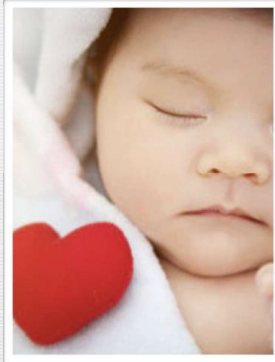
Cardiac Newborn Neuroprotective Network CNNN

- Google Group
- Special Interest Group of CNOG
- Twitter @NewbornCardiac
- Facebook
- jennifer.fogel@aah.org
- Samantha.butler@childrens.harvard.edu



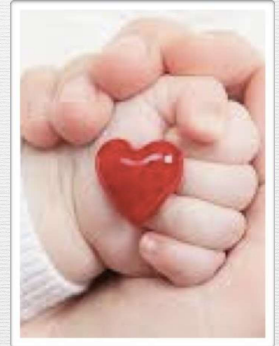
National Collaboratives

- Cardiac Neurodevelopment Outcomes Collaborative (CNOOC) 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



Thank You!

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