SINGLE VENTRICLE FEEDING TUBE WEANING CLINICAL PATHWAY

EXECUTIVE SUMMARY

Physician Owner(s): Kayla Grevengoed, PA-C & Abigail Phillips

Primary Objective

Patients with congenital single ventricle heart physiology often, out of necessity, require enteral feedings during the first year of life to promote optimal growth, maintain development, and provide fluids and nutrients as either an exclusive source, or supplementally.[6] This, over time, can create a reliance on enteral feedings to meet nutrition needs. Long term dependence on enteral feedings can delay development, create feeding aversions/intolerances, and create negative family experiences related to feeding. Establishing an enteral feeding tube weaning protocol for patients with single ventricle physiology will improve developmental outcomes for patients, and quality of life for the family unit.[6] This will impact patients followed in the Small But Mighty Clinic, with potential to expand to include patients with this type of physiology who are followed at outreach clinics. The tube weaning protocol will increase the number of these patients feeding all orally by 1 year of age to 84%.

Recommendations

Single Ventricle/Interstage Definition

The Small But Mighty clinic follows patients with single ventricle heart defects undergoing staged palliation between their 1st and 2nd palliation as well as patients who have a PDA stent placed to provide either systemic/pulmonary blood flow prior to getting full cardiac repair. Given the high-risk period with less stable physiology this population is in while seen in the Small But Mighty clinic, this pathway will be utilized for the population that was followed in the Small But Mighty clinic following either their 2nd stage palliation for single ventricles or full repair for PDA stent patients, when their physiology is more stable. For this pathway, we will use the smartpharse .svtubeweaningassessment [154974] to define our denominator. This will be based on criteria related to cardiac stability, swallowing safety and readiness, and nutritional adequacy and hydration. This information has been added to flowsheet rows to help define.

Feeds in Single Ventricle

Reliance on enteral feeding in children can reduce drive to eat by mouth, and cause feeding aversions, preventing further progression or oral intake.[5] Structured, hunger inducing weaning of small amounts of formula/enteral feedings provided via enteral tubes over time, has been shown to elicit improved oral feeding, and ultimate transition to fully oral eating. When medically appropriate, reducing the amount of enteral feeds provided by 20% from baseline every 3-7 days has been shown to improve the number of children able to eat exclusively orally by 60-88% at other centers who have implemented this pathway[1], per the NPC-QIC tube weaning toolkit. With close, multidisciplinary follow-up and consistent parent involvement in tracking potential negative outcomes (i.e. red flags outlined below) on a daily basis with weekly evaluation by the multidisciplinary team, patients can safely transition to oral feeding.

Red Flags

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Weaning enteral feedings to promote hunger drive does not typically produce immediate results. It can take days to weeks to regain normal hunger cues and meet 100% of nutrient and fluid needs by mouth. Some potential side effects of this protocol have been noted as red flags. These red flags were identified by the NPC-QIC toolkit and defined further by research and practical experience. Red flags include: meeting criteria for severe malnutrition (meeting <25% of the norm for expected weight gain for <2 years OR 10% weight loss for 2-20 years), clinical signs of dehydration (wet diapers ≤50% of normal output), vomiting/diarrhea, coughing/choking/signs of aspiration, and fatigue. Monitoring for red flags daily, can prevent negative impacts like excessive weight loss, aspiration, and dehydration.

Benefits of oral feeds

While the Small But Mighty clinic will be assisting the child with developing a hunger drive to promote increased oral intake, ultimately, it is the desire to promote positive oral feeding opportunities that allow the child to feel in control and never force-fed during the tube-weaning process. Positive oral feeding provides many benefits for the child and the family unit.[7] Eating orally allows the child to optimize age-appropriate oral skills in order to consume the least-restrictive, developmentally appropriate diet. It can also assist to normalize eating-related behaviors. This involves the sensory system, allowing the child to practice the skills needed to eat through touch, sight, smell, and taste. Additionally, it can allow normalization of the feeding environment, especially as it relates to the family unit during mealtimes. Introducing the child to the family mealtime routine, such as sitting in a highchair for all family mealtimes, can assist with the social aspects of family dynamics and encourage improved quality of life. Lastly, positive oral feeding experiences can lead to normalization of feeding regulation to encourage a feeding routine of 3 daily meals and 1-2 snacks to sustain a typical feeding pattern.

Rationale

Poor oral feeding is a common problem in single ventricle patients, with around 50% of infants following stage 1 palliation needing either full or supplemental nutrition via enteral tube.[4] Tube dependency has been shown to increase the risk of neurodevelopmental delay and have psychosocial impacts on patients and families with negative impact on quality of life and burden of care.[2,3] Tube fed patients require a multidisciplinary team to manage the tube, feeding regimen, and feeding therapy, leading to increased healthcare costs and time spent in medical appointments and therapy.

Between April 2017 - April 2023, the percentage of single ventricle patients in NPC-QIC who achieved all oral feeds by their 1st birthday was ~55% for the collaboration wide average, but only ~35% at Children's Hospital in Omaha. Many centers do not have a formal tube weaning process, so NPC-QIC developed a Tube Weaning Toolkit after extensive literature review and trialing at various pilot centers. The pilot centers had between 9% - 33% improvement in all oral feeds by first birthday using this toolkit.[1] The pathway we are using is modeled off the NPC-QIC Tube Weaning Toolkit, with goal to increase our center's average to 55% in the first year to match the national average.

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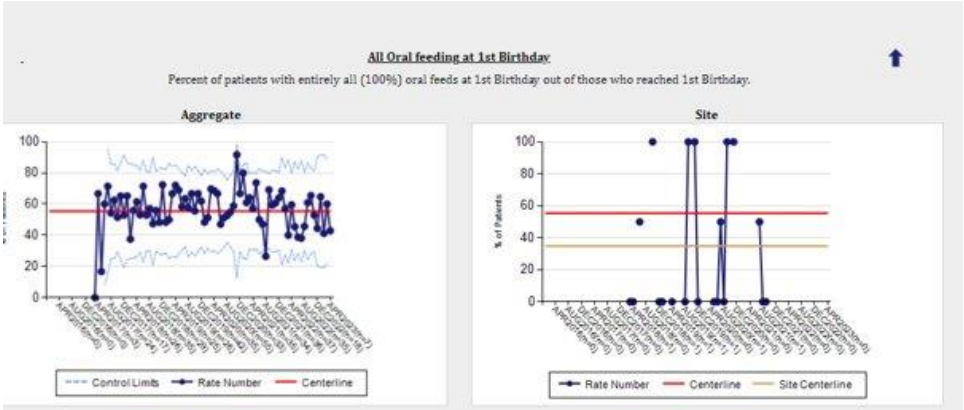

Risks of tube weaning include weight loss, dehydration, constipation and aspiration. These complications will be closely monitored for with frequent communication with families, education on "red flags" to watch for, and daily charting including weight, feeds, wet diapers, and stools, with at least weekly evaluation of these measures by the multidisciplinary healthcare team (dietitian, medical provider, feeding therapist).

Metrics

1. Outcome
    a. Increase single ventricle patients reach all oral feeding by 1 year of life to 55% by July/August 2024.
2. Process
    a. Increase utilization of note template once created to 80% by July/August 2024.
3. Balancing (an unintended consequence of the pathway)
    a. Monitor readmissions for dehydration and/or aspiration events.
    b. Monitor proportion of weight loss (>10% during an interval) during process.

Team Members

- Champion:
    - Kayla Grevengoed, PA-C, Single Ventricle APP
    - Abigail Phillips, Dietitian, Cardiology
- Team members
    - Melissa Wehrmann, MD, Cardiology
    - Jennifer Winter, MD, Cardiology
    - Chris Curzon, MD, Cardiology
    - Jeff Delaney, MD, Cardiology
    - Thomas Blount, MD, Cardiology
    - Kelly Hauschild, Interstage Nurse Navigator

- Lacie Riley, OT, Feeding therapist
- Shannon Frey, SLP, Feeding therapist
- Ashley Joy, Dietitian, GI
- Dr. Andrew Huang, MD, GI – ad-hoc

Evidence

1. NPC QIC Tube Weaning Toolkit https://static1.squarespace.com/static/5e8e4cdc4eebc8406b703e41/t/62684a5d7f4f094a65ca0b71/1651001953110/TubeWeaning_Toolkit_Final20220414.pdf
2. Medoff-Cooper B, Irving S, Aleaxandra L et al (2016) The association among feeding mode, growth, and developmental outcomes in infants with complex congenital heart disease at 6 and 12 months of age. J Pediatr 169:154–159
3. Pedersen SD, Parsons HG, Dewey D (2004) Stress levels experienced by the parents of enterally fed children. Child Care Health Dev 30(5):507–513
4. Sagiv E, Tjoeng YL, Davis M et all (2022) Assessing the Association Between Pre-operative Feeding and the Development of Oral Feeding Skills in Infants with Single Ventricle Heart Disease: An Analysis of the NPC-QIC Dataset. Pediatric Cardiology 43:1141-1155
5. Milligan C, Mills KI, Ge S, Michalowski A, Braudis N, Mansfield L, et al. Cardiovascular intensive care unit variables inform need for feeding tube utilization in infants with hypoplastic left heart syndrome. The Journal of Thoracic and Cardiovascular Surgery [Internet]. Available from: https://pubmed.ncbi.nlm.nih.gov/35691711/
6. Hartdorff, Caroline M.*; Kneepkens, C.M. Frank*; Stok-Akerboom, Anita M.†; van Dijk-Lokkart, Elisabeth M.‡; Engels, Michelle A.H.§; Kindermann, Angelika||. Clinical Tube Weaning Supported by Hunger Provocation in Fully-Tube-Fed Children. Journal of Pediatric Gastroenterology and Nutrition 60(4):p 538-543, April 2015. | DOI: 10.1097/MPG.0000000000000647
7. Bandstra C, Huston P, Zvonek K, Heinz C, & Piccione E. (2020). Outcomes for Feeding Tube-Dependent Children with Oral Aversion in an Intensive Interdisciplinary Treatment Program. Journal of Speech, Language, and Hearing Research, 63: 2497-2507.