Cardiology in the Young

cambridge.org/cty

Review

Cite this article: Desai H, Jones CE, Fogel JL, Negrin KA, Slater NL, Morris K, Doody LR, Engstler K, Torzone A, Smith J, and Butler SC (2023) Assessment and management of feeding difficulties for infants with complex CHD. *Cardiology in the Young* **33**: 1–10. doi: 10.1017/S1047951122004024

Received: 13 July 2022
Revised: 21 October 2022
Accepted: 23 November 2022
First published online: 23 December 2022

Keywords:
Oral feeding; complex CHD; feeding difficulties; dysphagia assessment; dysphagia management

Author for correspondence:
Hema Desai, MS CCC-SLP 1201 LA Veta, Orange, CA 92868, USA. Tel: +1 714 482 6990.
E-mail: hdesai@choc.org

© The Author(s), 2022. Published by Cambridge University Press.

Assessment and management of feeding difficulties for infants with complex CHD

Hema Desai[1], Courtney E. Jones[2], Jennifer L. Fogel[3], Karli A. Negrin[4], Nancy L. Slater[5], Kimberly Morris[6], Lisa R. Doody[7], Katherine Engstler[8], Andrea Torzone[9], Jodi Smith[10] and Samantha C. Butler[11]

[1]Department of Rehabilitation Services, Children's Hospital of Orange County, Orange, CA, USA; [2]Acute Care Therapy Services, Primary Children's Hospital, Salt Lake City, UT, USA; [3]Department of Pediatric Rehabilitation, Advocate Children's Hospital, Oak Lawn, IL, USA; [4]Department of Therapy and Rehabilitative Services, Nemours Children's Health, Wilmington, DE, USA; [5]Physical Medicine and Rehabilitation Services, Children's Minnesota, Minneapolis, MN, USA; [6]Department of Speech-Language Pathology, Rady Children's Hospital San Diego, San Diego, CA, USA; [7]Pediatric Rehabilitation and Development, Advocate Children's Hospital, Oak Lawn, IL, USA; [8]Department of Otolaryngology and Communication Enhancement, Boston Children's Hospital, Boston, MA, USA; [9]Heart Center, Cardiac Intensive Care Unit, Children's Medical Center Dallas, Dallas, TX, USA; [10]Mended Hearts Inc., Albany, GE, USA and [11]Harvard Medical School, Boston Children's Hospital, Boston, MA, USA

Abstract

Early surgical intervention in infants with complex CHD results in significant disruptions to their respiratory, gastrointestinal, and nervous systems, which are all instrumental to the development of safe and efficient oral feeding skills. Standardised assessments or treatment protocols are not currently available for this unique population, requiring the clinician to rely on knowledge based on neonatal literature. Clinicians need to be skilled at evaluating and analysing these systems to develop an appropriate treatment plan to improve oral feeding skill and safety, while considering post-operative recovery in the infant with complex CHD. Supporting the family to re-establish their parental role during the hospitalisation and upon discharge is critical to reducing parental stress and oral feeding success.

Infants with complex CHD who require surgical intervention experience significant disruptions in their first few months after birth which impact their ability to feed orally. Twenty-two to 50% of children with complex CHD experience feeding challenges.[1–3] Structural and physiologic cardiopulmonary differences in the infant with complex CHD impact neurodevelopment, as well as the respiratory and gastrointestinal systems, all of which are instrumental to promoting safe and efficient oral feeding. Understanding the medical complications and physiology of children with complex CHD is important in the assessment and treatment of feeding difficulties in order to change long-term trajectories with early intervention. Medical complications impacting the neurological, gastrointestinal, and respiratory systems after surgery and its disruptions to feeding development have been discussed in great detail.[4] The current manuscript reviews assessment and treatment of oral feeding skills in the infant with complex CHD, taking into consideration the unique medical consequences which impact feeding development.

Respiratory

Infants born with complex CHD often require respiratory support both before and after surgical intervention. The need for respiratory support interferes with opportunities for natural oral stimulation and oral feeding due to the placement of the endotracheal tube or non-invasive respiratory support equipment and the physiological status of the infant.

Assessment

Currently, standardised protocols to assess oral feeding readiness and swallowing safety while an infant is receiving higher levels of respiratory support are not available.[5] Literature looking at safety of oral feeding for preterm infants on nasal continuous positive airway pressure and high-flow nasal cannula reveal inconsistent results, with some indicating little to no impact on swallowing safety while others revealing an increased risk for aspiration.[6–8] The flow rate of high-flow nasal cannula or continuous positive airway pressure at which suck/swallow/breathe coordination is disrupted is currently unknown, as contributing factors such as weight, air leak, and individual patient physiology result in variable positive pressure generation.[9] Infants on high-flow nasal cannula with a flow rate as low as 2.5 L/min can generate levels of positive pressure that increase the risk for swallowing dysfunction.[10] Institution specific protocols should take into consideration respiratory status, oral feeding readiness cues, oral motor and swallowing coordination, and endurance to determine safe level for small volume of therapeutic feeding trials for infants with acute respiratory illness on high-flow nasal cannula.[11]

Recommendations

Infants born with complex CHD often have delayed experiences with oral sensory stimulation, which are important for the development of neuromotor and sensory pathways responsible for the establishment of oral sensory motor and feeding skills.[7] Early intervention by skilled feeding therapists can help promote improved oral motor strength, coordination, and sensory processing.[12]

Non-nutritive oral motor stimulation has been proven to shorten time to nutritive oral feeding in infants and decrease length of hospital stay in infants with single ventricle anatomy in the cardiac ICU compared to infants who did not receive the intervention.[12] Providing oral stimulation with a small volume (e.g., 0.2 ml) of colostrum or human milk facilitates sensory stimulation. The anti-microbial and anti-bacterial properties of colostrum and human milk may help with decreasing permeability in the gut lining[13,14], thus reducing risk for necrotising enterocolitis, ventilator-associated pneumonia, and sepsis.[15–17] If the infant tolerates a small presentation of milk and does not exhibit stress signs while intubated, additional stimulation can be provided to the body of the tongue with the swab or a tiny pacifier under the intubation tube to facilitate lingual cupping in a gentle/respectful approach. When the infant tolerates non-invasive respiratory support (Non-invasive Neurally Adjusted Ventilatory Assist (NIV-NAVA), high-flow nasal cannula, or nasal continuous positive airway pressure), a pacifier or finger dipped in human milk can be offered to encourage lingual/palatal proprioceptive awareness, improve oral seal, increase lingual movement, and improve strength for later bolus control once bottle or breastfeeding begins. Reading infant cues while providing oral stimulation is critical to ensure positive oral experiences. Signs of stress might include colour changes, frowning, finger splaying, stretching out arms and legs, decreasing or increasing heart rate, and gagging.

There can be oral sensory deprivation or overload when learning to eat which needs to be in careful balance for success.[7] While initiating early oral feeding is important, a slow transition is often necessary toward bottle or breastfeeding. Encouraging an infant to suck on their own hand with milk promotes hand to mouth movement and improved proprioceptive awareness for pre-feeding skills. When beginning with breast or bottle feeding, the infant may be able to start with a small volume (e.g., 3–5 ml twice a day) if showing feeding readiness such as an awake state, rooting, or spontaneously bringing hands to mouth while still on high-flow respiratory support. Use of the slowest flow nipple to control the bolus and elevated side-lying position (Fig 1) to decrease the impact of gravity and improve breathing are strategies that can be implemented as an infant is weaning from respiratory support.

Skilled therapists can initiate therapeutic trials and advance volume or increase duration of time or frequency of feeding based on the infant's behavioural responses to stimulation, progression in weaning from respiratory support, improved cardiorespiratory endurance, and tolerance of enteral feedings. Clinical pathways such as The Safe Individualized Nipple Feeding Competence can be effective if done consistently and according to the protocol.[7] Safe Individualized Nipple Feeding Competence is a systemic approach to safe and slow progressive oral feeding experiences based upon age, behavioural cues, respiratory support, and per cent of total volume the patient needs for nutrition.[7]

Figure 1 Side-lying position: head, shoulder, and hips supported midline, exposed ear pointing towards the ceiling, hands swaddled near the infant's face.

Gastrointestinal

Infants with complex CHD often experience gastrointestinal difficulties after cardiac surgery due to multiple causes, with vagal nerve dysfunction being the most highly cited in the research literature.[18] Twenty-five per cent of infants with complex CHD experience gastroesophageal reflux disease compared to 10–20% of infants without complex CHD, though this may be a low estimate due to difficulty diagnosing in the infant population.[19–22] Gastroesophageal reflux disease may cause discomfort and/or respiratory compromise, resulting in poor oral intake, and difficulties with weight gain. Most infants are diagnosed with gastroesophageal reflux disease based on clinical symptoms (i.e., coughing, irritability, apnoea, feeding difficulties).[23] Pharyngeal and oesophageal motility may also be compromised after cardiac surgery due to transesophageal echocardiography and sedation/medication resulting in difficulties with oral feeding progression. Furthermore, inflammation, surgical/visceral trauma, circulatory changes, and chronic ventilation can alter sensorimotor reflexes of the pharynx and oesophagus.

Assessment

Collaboration with a gastroenterologist is beneficial to identify appropriate diagnostic testing to diagnose and manage gastrointestinal symptoms. An upper gastrointestinal tract series, oesophageal pH probe monitoring or multichannel intraluminal impedance with pH (pH-MII) can be performed to detect acid reflux and determine correlation between symptoms and acidic reflux episodes. High-resolution manometry is a diagnostic tool to assess motility difficulties when an infant presents with persistent oral feeding progression challenges in light of typical oral motor and pharyngeal swallowing skills. Diagnostic testing is beneficial and has been researched in infants with complex CHD to guide medical

https://doi.org/10.1017/S1047951122004024 Published online by Cambridge University Press

management, especially if symptoms are atypical and not responsive to treatment strategies.[24]

Recommendations

Management of gastroesophageal reflux disease is critical in promoting positive oral feeding experiences and feeding progression, as studies have shown increased feeding difficulties in children with gastroesophageal reflux disease, impacting their growth and development.[25] Non-pharmacologic management has been recommended as the initial treatment for infants with gastroesophageal reflux disease, followed by a limited trial of medication.[26] Thickening formula or expressed breastmilk, with careful oversight, and using extensively hydrolysed protein formula are strategies used to decrease vomiting and reflux episodes.[24,27] Positioning in the left lateral position is noted to decrease the severity of vomiting on pH impedance testing in symptomatic infants with gastroesophageal reflux disease.[28] Decreasing infant stress via skin-to-skin and supporting breastfeeding to improve gut microbiome and reduce discomfort are also interventions used to potentially improve symptoms of gastroesophageal reflux disease.[18,24] Anti-reflux medications have been widely used to treat reflux in infants. However, there is evidence suggesting that these medications do not have an effect on reducing gastroesophageal reflux disease symptoms in infants and may increase risk of abnormal bacterial colonisation and infections.[18] The literature, along with expert clinical consensus, recommends use of proton-pump inhibitors for the treatment of symptoms of reflux (e.g., erosive oesophagitis) in infants, but not for clinical signs (distress, fussiness, visible regurgitation) in otherwise healthy infants.[26] Erythromycin is the only promotility agent with proven effectiveness in improving gastric motility and feeding tolerance in preterm infants.[29] In addition, abdominal massage has also been found to increase vagal nerve activity and improve gastric motility in preterm infants.[30]

Nutrition

Infants with complex CHD present with challenges with weight gain due to hypermetabolism, increased demand on respiratory muscles resulting in tachypnoea, and poor endurance to consume sufficient volumes to meet caloric needs.[4]

Assessment

The World Health Organization provides guidelines for nutritional assessment standards and integrated anthropometric classification which include weight, length and head circumference measurements, nutritional lab results, dietary intake, medical complexity, illness severity, energy requirements, and clinical observations of fat stores, mucous membrane,s and skin colour changes.[31–33] With a complete nutritional assessment, interventions can be determined to promote growth and development, providing safe perioperative nutrition.[34–38] The dietitian is also a crucial team member in decision and timing of gastrostomy tube placement.

Recommendations

Dietitians provide recommendations for individualised nutrition and hydration for critically ill infants.[39] Management of proper nutrition may include fortified human milk or formula to meet the energy needs of the infant, which are increased for infants with complex CHD especially when in recovery.[40,41] Fat-free formula or fat-free human milk and dairy-free alternative may be used to support recovery from chylothorax and medical necrotising enterocolitis, respectively, after a period of gut rest or nothing by mouth.[42] Feeding advancement algorithms to methodically increase volume can improve intestinal comfort and decrease time to full enteral feeds.[35]

The way an infant's nutrition is advanced post-operatively can affect intestinal comfort and tolerance. As tube feeding is advanced and the amount of food is increased over time, the infant's response to the nutrition impacts oral feeding readiness. If the infant has poor tolerance for tube feeding this can negatively impact the infants' oral feeding cues and delay eating by mouth. Signs that infants are not tolerating tube feeding include gagging/retching, increased fussiness, frequent emesis, bilious emesis, increased abdominal girth, and poor tolerance to oral stimulation such as taking pacifier or touch near the mouth, bloody stool, high stool output, and overall discomfort. The medical team, including the dietitian and feeding therapist, should work together to promote adequate nutrition, intestinal comfort with tube feedings, positive oral motor experiences, and creation of a plan to support oral feeding. The dietitian's role perioperatively is crucial to ensure the infant receives adequate nutrition to recover and grow[41,43] in order to demonstrate sufficient endurance for oral feeding trials.

Bottle feeding

Delayed oral motor skill and coordination contributes to oral feeding challenges in infants with complex CHD due to respiratory, neurological and gastrointestinal comorbidities.[4]

Assessment

There is currently no standardised oral feeding assessment to evaluate the bottle-feeding abilities of infants with complex CHD. As a result, clinicians must rely on other evaluation tools which have been primarily based on data collected in the preterm population. The Early Feeding Skills Assessment[44], the Neonatal Oral Motor Assessment Scale[45], the Neonatal Eating Assessment Tool – Bottle Feeding[46,] and the Neonatal Eating Outcome Assessment[47] have all been developed for clinical use in the preterm population. The Early Feeding Skills takes a holistic approach to feeding, assessing behavioural state, feeding readiness, muscle tone, energy level, behavioural stress signs, swallowing, physiologic stability, and oral motor function.[48] It has acceptable internal consistency reliability and construct validity and is available for clinicians from the first author.[49] The Neonatal Oral Motor Assessment Scale focuses primarily on oral motor skills for sucking, with two test questions regarding fatigue and suck/swallow/breathe incoordination.[48] It can be used for either bottle or breastfeeding and has been used in many other research studies to quantify an infant's oral motor skills.[50,51] The Neonatal Eating Assessment Tool – Bottle Feeding is a valid and reliable parent report measure to assess infant bottle-feeding skills based on scores on five subscales looking at gastrointestinal tract function, infant regulation, energy and physiological stability, sensory responsiveness, and symptoms of problematic feeding.[46] The Neonatal Eating Outcome assessment is also a standardised assessment of feeding skills for premature infants which can be used to identify feeding difficulties and provide appropriate interventions. Bickell et al. 2018 reviewed the Oral Feeding Scale[52], which provides objective measure of skill and endurance, but does not assist in identifying oral motor dysfunction which may impact oral feeding.[51,52]

https://doi.org/10.1017/S1047951122004024 Published online by Cambridge University Press

Ehrmann et al. 2017 described a standardised feeding readiness assessment, adapted from a previously validated guideline, systematically measured feeding readiness in eight stages ranging from pre-feeding skills to nutritive sucking to help predict the need for enteral tube feeds.[53] While these assessment tools will allow a clinician to look at feeding skills holistically, they do not take into consideration the complexity of post-operative recovery of the infant with complex CHD.

Recommendations

When facilitating feeding skills in children with complex CHD, maintaining cardiorespiratory stability and safe oropharyngeal swallowing function should be considered. Positioning an infant in side-lying has been used to support less variation of oxygen saturations during feedings, increased saturations in the middle of feedings, and respiratory rates closer to baseline compared to infants held in a supine or semi-upright position.[54] The elevated side-lying position may improve oral transit control by optimising slower bolus flow through reduction of hydrostatic pressure in the bottle. This position can also promote improved chest wall movement and airway patency by decreasing the gravitational effects on rib cage expansion. The use of side-lying position and co-regulated pacing also attempts to mimic the physiologic norm of breastfeeding.[54,55]

Another common feeding technique to promote physiologic stability is co-regulated paced bottle feeding[55] which includes attention to the number of suck/swallow combinations before a breath and physiologic stability. Implemented rest breaks periodically during a feeding may improve energy level and breathing rate, but this has not been directly researched in children with complex CHD. In addition, changing the bottle nipple to alter the rate of milk flow is a strategy that has been shown to improve physiologic stability during bottle feeding in term and preterm infants.[56,57] Faster flow rate nipples lead to larger bolus size, requiring the infant to compensate by increasing frequency of swallowing or holding their breath for a longer duration (in order to swallow a larger bolus), which can result in decreased ventilation.[58] While typically developing infants maintain adequate oxygenation by altering their sucking pattern in response to milk flow, it is unclear if infants with complex CHD are as capable.[59] The use of slower flow nipples may allow the infant to have more opportunities to breathe, maintain physiologic stability, and feed more efficiently.

Breastfeeding

Breastfeeding is often challenging for infants with complex CHD due to initial separation of infant from mother for surgery, lack of privacy in the ICU, inability to measure volumes and belief of breastfeeding being more difficult than bottle feeds.[4] Additionally, there is poor consensus regarding clinical practice to support breastfeeding in this population.[60]

Assessment

Assessing and supporting breastfeeding perioperatively should be standard for infants with complex CHD if possible. Unfortunately, there are no formal breastfeeding assessments specific to infants with complex CHD. The Bristol breastfeeding assessment tool was developed for healthy full-term infants to increase efficacy and maternal self-confidence.[61] The LATCH is a breastfeeding charting system consisting of a five-item assessment of the following: latch, audible swallowing, type of nipple, comfort of breast and holding.[62] It was developed by experts but does not have a target population, formal content validity, or consistency between raters.[48] Studies comparing healthy newborns and predicting long-term feeding success have revealed that the higher the LATCH score, the more likely the infant will be breastfeeding at 6 weeks postpartum.[63] The Neonatal Eating Assessment Tool - Mixed Feeding is a parent report of 68 measures of breast and bottle-feeding behaviour for infants less than 7 months and demonstrates validity and reliability to identify infants with problematic feeding in order to intervene appropriately.[64] Informal assessments of breastfeeding can be completed by lactation specialists and feeding therapists with a focus on transitioning the infant to the breast as soon as possible. Providing supports such as best positioning, assessing, and assisting with the infant's latch, monitoring swallowing safety, pacing at the breast or pre-pumping through the mother's let down and offering devices such as nipple shields are beneficial to assist with breastfeeding goals.

Recommendations

Interventions to support the breastfeeding infant with complex CHD vary across the nation. Breastfeeding is an established safe practice for infants with complex CHD, with the benefits of human milk and supporting the mother-child dyad well documented.[65] The literature supports the potential for improved physiologic stability and oxygenation in breastfeeding compared to bottle feeding.[66] Contributing factors include the opportunity for natural positioning (e.g., cross cradle hold), independent control of flow rate, benefits of skin-to-skin, and natural rest breaks between letdowns which could improve minute ventilation.[67]

Supporting early and consistent development of this unique motor planning and programming at the breast is essential for establishment of the least restrictive feeding plan for children with complex CHD.[67,68] Studies have demonstrated improved timing to full breastfeeding with the simple introduction of skin-to-skin in typically developing infants and in infants with complex CHD.[69–71] Skin-to-skin can safely be offered perioperatively with the adoption of ICU holding protocols.[71] Additionally, supporting the breastfeeding mother during the tumultuous perioperative period with easy access to hospital-grade breast pumps, preferably in the patient's room to facilitate skin-to-skin or non-nutritive breastfeeding after pumping. Other supports include the use of pasteurised donor milk to support transitions to the mother's full human milk supply, and hospital supported milk centres to ensure safe management of human milk. Recommendations include early and frequent lactation support during the time breastmilk supply is established, ensuring the mother is receiving adequate nutrition and hydration (some centres provided a meal daily for breastfeeding mothers) and assuring mothers have a hospital-grade pump at discharge.[65]

Coordinated sucking on a pacifier and holding along with pacifier use during tube feeding has demonstrated faster transition to breastfeeding in preterm infants[72] and a reduction in the duration of hospital stay.[73]

Dysphagia

Perinatal events and medical or surgical interventions may impact neurosensory and neuromotor pathways, leading to maladaptive oral feeding patterns and a diagnosis of oropharyngeal dysphagia or swallow dysfunction.[74] Infants receiving a stage 1 palliation and aortic arch reconstruction are at high risk for recurrent laryngeal

https://doi.org/10.1017/S1047951122004024 Published online by Cambridge University Press

nerve injury, with 48–59% resulting in vocal cord paresis/paralysis and subsequent dysphagia.[75–79] Though the presence of vocal fold paresis increases risk of dysphagia, studies describe higher incidence of dysphagia in children born with complex CHD even without vocal fold paresis.[80,81] For note, the majority of infants with complex CHD and aspiration have normal vocal fold function and are asymptomatic.[82] Prematurity is an added risk factor for dysphagia for infants with complex CHD.[83]

Assessment

The Videofluoroscopic Swallow Study [also referred to as the Modified Barium Swallow Study] and Fiberoptic Endoscopic Evaluation of Swallow are considered the gold standards in the evaluation of the swallow mechanism, with known benefits and limitations to assist with clinical decision-making. Both are instrumental evaluations which assess the anatomical and physiologic characteristics of the oropharyngeal swallow to determine pathology that contributes towards swallowing disorders and ultimately airway threat from a bolus. The Videofluoroscopic Swallow Study allows for observation of the oral, pharyngeal, and cervical oesophageal phases of the swallow.[84] It is performed by a feeding therapist and radiologist to allow for implementation of feeding strategies such as nipple flow modification, external pacing, thickening, and positional change that may be useful in improving swallowing function and decreasing risk for aspiration. Fiberoptic Endoscopic Evaluation of Swallow is usually performed by a speech pathologist in collaboration with an otolaryngologist to directly visualise the nasal, pharyngeal and laryngeal structures during swallowing. Fiberoptic Endoscopic Evaluation of Swallow may be performed on an infant while breastfeeding and can be completed at bedside for infants in the intensive care unit.[85]

Recommendations

Alterations to liquid viscosity is a treatment method in the management of infant pharyngeal phase dysphagia.[86,87] Although not completely understood, it is thought that the sensory input from the thickened liquids impacts timing of oral and pharyngeal transfer of the bolus, duration of upper oesophageal sphincter opening as well as magnitude of hyoid and laryngeal vestibule movements.[88–90] Thickening infant formula and breastmilk does not come without controversial clinical application and should not be the first intervention used for treatment of pharyngeal phase dysphagia. McGratten et al 2017 studied dysphagia in infants following stage 1 surgical palliation revealing that nectar thick barium, compared to thin barium contrast, allowed significantly more infants to swallow without aspiration.[81] In this same study, an increase in viscosity to nectar thick resulted in significant extraction challenges such as increased number of sucks to form a bolus. In addition, increased viscosity may not be a viable solution for infants with complex CHD who aspirate due to energy expenditure and continued aspiration risk.[81] Large quantities of starch-based thickeners may negatively impact the immature and maladaptive infant gut resulting in malabsorption, necrotising enterocolitis, shift of macronutrient composition and constipation. Concerns also include arsenic exposure with use of rice cereal to thicken and reduction or discontinuation of human milk due to viscosity maintenance challenges.[91–93] Extended use of thickened liquids may contribute to atypical motor planning of swallow, lending to challenges with weaning to thin liquids when indicated.[94] Unfortunately, without direction, many clinicians caring for infants with complex CHD have little to no guidance of thresholds for introduction of thickened liquids as a dysphagia treatment for this vulnerable population with variability of clinical practices.[95] Support from a skilled feeding therapist is recommended in determination of thickening liquids to manage dysphagia.

The infants' safe swallowing impacts oral acceptance and protects positive oral stimulation for long-term oral feeding. Timing of long-term supplemental nutrition via gastrostomy tube and the influence on promoting or hindering oral feeding development should be considered individually and addressed globally for our infants with complex CHD.

Neurodevelopment

Neurodevelopmental abnormalities are common and documented in greater than 50% of newborns with complex CHD before surgery with abnormality persisting after surgery.[96–100] These challenges can affect the infant's ability to develop higher level motor and cognitive skills for safe and efficient oral feeding. Neurodevelopmental testing on newborns has demonstrated poor state regulation and decreased motor skill development, including oral motor skills.[98,99] Stability in autonomic state, sensorimotor system, and behavioural state are critical for the complex process of coordinating sucking, swallowing, and breathing. Unfortunately, decreased attention is often a concern for infants with complex CHD and is associated with poorer oral feeding outcomes.[101] In addition, behavioural state regulation to transition from sleep to alert state is necessary to interact with the environment and take adequate nutrition for growth.[102]

Assessment

Several infant measurements are helpful to review infant neurodevelopmental strength and weakness. The developmental assessment measures which are based on the Brazelton Neonatal Behavioral Assessment Scale[103] such as the Newborn Behavioral Observations,[104] Assessment of Preterm Infants' Behavior,[105] and NICU Network Neurobehavioral Scale,[106] all measure infant state, motor skills, autonomic stability, self-regulation, and social interaction. The NICU Network Neurobehavioral Scale-II has been used most often on research of infants with complex CHD and examines both neurologic integrity as well as behavioural functioning and scores a full range of infant neurodevelopmental performance that was intended to have broad applicability for detecting at-risk infants and has been correlated with infant feeding.[99,101] The Newborn Behavioral Observations system has also been used in children with complex CHD and is an infant-focused, family centred, relationship-based tool, designed to sensitise parents to their infant's competencies and individuality to foster positive parent-infant interactions and provide early support to the relationship.[99] The Newborn Behavioral Observations itself is not an assessment but is a set of shared observations designed to help the clinician and parent to collaborate, observe the infant's behavioural capacities and identify the best support for successful growth, oral feeding and overall development.[104]

Recommendations

The Supporting of Oral Feeding in Fragile Infants method is an evidence-based strategy which has been used with preterm infants to assess and reassess infant cues and use neurodevelopmental strategies to respond to the cues.[107] Auditory, Tactile, Visual, and Vestibular is a multisensory intervention that has been found

https://doi.org/10.1017/S1047951122004024 Published online by Cambridge University Press

to improve sucking organisation and pressure in preterm infants by facilitating behavioural organisation and alert state.[108,109] Sensory strategies are utilised to decrease infant stress signs and promote behavioural subsystem stability to achieve oral feeding readiness. Recognition of infant stress signs and use of neurodevelopmental strategies such as decreasing the challenge, providing external postural support via swaddling, reducing environmental stimulation, and providing gentle touch can facilitate a more organised response to the feeding intervention.[102,110]

In addition, the Newborn Individualized Developmental Care and Assessment Program is an intervention which is theory-based and supported by scientific evidence.[111] The model focuses on detailed reading of each individual infant's behavioural cues. These cues dictate the environmental and care adaptations that are required to support and enhance each infant's strengths and self-regulation capacities. Newborn Individualized Developmental Care and Assessment Program has been shown to improve outcomes for infants including decreased hospital stay, decreased days on tube feeding and increased weight gain in preterm infants and is recommended in infants with CHD.[108,112–113]

Multidisciplinary team

It is important to foster and value a team approach to feeding safety and skill development. Collaboration among feeding therapists, bedside nurses, developmental therapists, families, and physicians/advanced practice providers is necessary for successful feeding of newborns and infants with complex CHD. Each team member has unique and critical insight regarding how best to optimise the feeding approach. This begins with formal and informal discussions of patient-specific goals for growth and nutrition based on cardiopulmonary status, which then guide establishment of a feeding plan post-clinical assessment. The bedside nurse plays a key role in gathering relevant information that guides the daily medical plan and implementation of feeding practice. However, advanced paediatric feeding assessment, pre-feeding interventions, neurodevelopmental support, and modulation of therapeutic techniques are not taught in undergraduate nursing programmes. A structured support system for bedside nurses to advance their knowledge of common feeding strategies is recommended to carry over targeted feeding behaviours and skills throughout the day. Educational strategies can be implemented via in-services, hands-on skills labs, shadowing of feeding therapists, and most importantly demonstration and discussion when feeding plans are being established and implemented at bedside. Feeding therapists and bedside nurses can also educate and train parents to implement strategies to be able to feed their child safely and successfully during hospital admission. Automatic order sets are helpful to allow for immediate pre-feeding and feeding support with referrals to feeding therapist along with supports for overall neurodevelopment through physical therapy, occupational therapy, child life, and neurodevelopmental specialists.

Family support

Lisanti and colleagues (2017) examined maternal stress and anxiety in mothers of infants in the paediatric cardiac intensive care unit and found the greatest maternal stressors to be infants' appearance and behaviour, followed by parental role alteration.[114] Supporting families to re-establish their roles as a primary caretaker and decision-makers can be implemented as early as the first day of life for a baby who is intubated through education and information sharing.[115]

Options for outpatient therapy after discharge

Infants with complex CHD discharged with a feeding tube or with other feeding challenges require skilled feeding therapy after discharge. The American Heart Association recommends early intervention for all infants with complex CHD upon discharge from primary interventions, which could include feeding therapy.[116] Utilisation and timing of services varies by location in the United States. Often infants can receive feeding therapy through their local Early Intervention programme, through private feeding therapists in the community or through a hospital-based feeding programme. Coordinating feeding therapy can be difficult to navigate, especially when an infant's surgical intervention is in a different state than their residence. The local paediatrician, cardiologist, and hospital case managers can help support referral to feeding therapy close to home. Recently, cardiac-specific feeding clinics have been developed to support the transition from discharging with a feeding tube and tube weaning. Cardiac feeding clinics can be provided in conjunction with follow-up cardiac neurodevelopmental programmes or cardiology medical visits.

Weaning from the feeding tube typically happens post-discharge home and can be especially challenging for children with complex CHD. Often providers of children with complex CHD are concerned about weight gain and growth and less likely to agree to decreasing calorie intake through tube usage while working on increasing hunger and encouraging oral feeding. A systematic review and meta-analysis of weaning programmes for toddlers ages 15–48 months (27% with cardio/pulmonary medical concerns), including intensive day treatment and/or inpatient hospital programmes, reported that dependence on tube feeding was eliminated in 71% of children at discharge from the feeding programme. When follow-up data was provided at an average of 9 months post-treatment, 80% of these patients were able to maintain independence from tube feedings after the formal intervention.[117] Key components for successful tube weaning in the toddler population included utilisation of a multidisciplinary team, hunger provocation, behavioural interventions, positive mealtimes and oral experiences, and caregiver involvement.[118] Tube weaning duration is variable depending on the treatment approach and intensity, taking between three weeks up to four months.[119]

Conclusions

Treatment and management of oral feeding challenges in the pre- and post-operative period in the infant with complex CHD requires attention to multisystem factors which all need to interact together to develop and maintain safe and efficient oral feeding and swallowing skills. Clinicians need to be skilled at evaluating and analysing the systems which impact oral feeding such as respiratory, neurological, and gastrointestinal. Use of appropriate feeding strategies can facilitate improved respiration, endurance and swallow safety during bottle or breastfeeding. In addition to aiding the infant during the hospitalisation, the family also should be supported to reduce stress and re-establish their role as a parent in the care of their child. The family and the infant benefit from continued support after discharging from the hospital through outpatient therapy services and nutrition guidance to achieve oral feeding goals (Table 1).

Despite the considerable evidence for feeding challenges in infants with CHD, specific assessment tools and intervention strategies which consider their unique post-surgical sequelae have not yet been established. Current clinical practice to improve oral

https://doi.org/10.1017/S1047951122004024 Published online by Cambridge University Press

Table 1. Summary of feeding assessments and management recommendations

	Feeding disruptions for infants with CHD[4]	Assessment	Management strategies
Respiratory	• Delayed oral experiences • Tachypnoea • Level of respiratory support • Swallowing/breathing coordination • Haemodynamic stability	• None	• Early and skilled feeding therapy • Pre-feeding activities ○ Non-nutritive oral stimulation ○ Oral taste trials ○ Small volume of colostrum swab ○ Upright positioning ○ Head and trunk control activities ○ Skin-to-Skin kangaroo care ○ Chest-to-chest positioning ○ 4-handed cares ○ Modified environment • Slow flow nipple-bolus control • Elevated side-lying position • Infant cue-based feeding • Safe Individualized Nipple Feeding (SINC)
Gastrointestinal	• GERD • Pharyngeal dysmotility • Oesophageal dysmotility • Chylothorax • Pneumatosis • Necrotising enterocolitis • Feeding intolerance	• Upper gastrointestinal tract series • Oesophageal pH probe • Multichannel intraluminal impedance with pH • High-resolution manometry	• Gastrointestinal consult • Diagnostic testing • Early and skilled feeding therapy • Thickened feeds • Specialised formula • Left lateral feeding position • Developmental calming • Anti-reflux medications • Promotility agents • Non-pharmacologic management • Pre-feeding activities (see above)
Neurological	• Oropharyngeal dysphagia • Vocal fold paresis • Diaphragm paresis • Seizures • Strokes • Neurodevelopment abnormalities	• Videofluoroscopic swallow study • Flexible endoscopic evaluation of swallowing • Flexible Fiberoptic Laryngoscopy	• Instrumental assessment • Side-lying positioning • Co-regulated bottle feeding • Nipple flow rate • Thickened feeds • Neurodevelopmental calming • Pre-feeding activities (see above)
Nutrition	• Growth/repair nutrition disparity	• Weight • Length • Head circumference • Weight for length z-score • World Health Organization Guidelines	• Individualised nutrition plans • Formula and human milk fortification • Supplemental nutrition • Specialised formula
Bottle feeding	• Delayed experience • State	• Early Feeding Skills Assessment (EFS) • Neonatal Oral Motor Assessment Scale (NOMAS) • Neonatal Eating Assessment Tool – Bottle Feeding (NeoEAT-Bottle Feeding) • Neonatal Eating Outcome (NEO)	• Pre-feeding interventions (see above) • Neurodevelopmental calming • Musculoskeletal organisation • Infant cue-based feeding • Positioning • Nipple flow rate • Safe Individualized Nipple Feeding (SINC) • Supporting of Oral Feeding in Fragile Infants (SOFFI) method
Breastfeeding	• Delayed experience • Separated parent-child dyad	• Bristol breastfeeding assessment tool • NeoEAT-Mixed Feeding	• Positioning strategies • Pre-feeding activities • Neurodevelopmental calming strategies • Parent-child dyad support • Supporting of Oral Feeding in Fragile Infants (SOFFI) method
Neurodevelopment	• Noxious environment • Separated parent-child dyad • Neurodevelopment abnormalities	• Brazelton Neonatal Behavioral Assessment Scale (NBAS) • Newborn Behavioral Observations (NBO) • Assessment of Preterm Infants' Behavior (APIB) • NICU Network Neurobehavioral Scale (NNNS)	• Supporting of Oral Feeding in Fragile Infants (SOFFI) method • Auditory, Tactile, Visual, and Vestibular (ATVV) • Newborn Individualized Developmental Care and Assessment Program • Automatic orders for OT/PT/SP

feeding difficulties in this population applies knowledge based on neonatal literature. However, we are uncertain if these practices are effective for infants with CHD, as there are significant gaps in the research examining assessment and intervention strategies. Additional studies exploring oral feeding with non-invasive respiratory support, gastrointestinal complications and effect on oral feeding development and feeding outcomes with use of common therapeutic feeding strategies in infants with CHD are some

https://doi.org/10.1017/S1047951122004024 Published online by Cambridge University Press

examples of future research that is necessary to facilitate treatment and management of the complex feeding difficulties in this population.

Acknowledgements. None.

Funding. This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

Conflict of interest. None.

References

1. Maurer I, Latal B, Geissmann H, Knirsch W, Bauersfeld U, Balmer C. Prevalence and predictors of later feeding disorders in children who underwent neonatal cardiac surgery for congenital heart disease. Cardiol Young 2011; 21: 303–309.
2. Skinner ML, Halstead LA, Rubinstein CS, Atz AM, Andrews D, Bradley SM. Laryngopharyngeal dysfunction after the Norwood procedure. J Thorac Cardiovasc Surg 2005; 130: 1293–1301.
3. Yi SH, Kim SJ, Huh J, Jun TG, Cheon HJ, Kwon JY. Dysphagia in infants after open heart procedures. Am J Phys Med Rehab 2013; 92: 496–503.
4. Jones CE, Desai H, Fogel JL, et al. Disruptions in the development of feeding for infants with congenital heart disease. Cardiol Young 2021; 31: 589–596.
5. Canning A, Fairhurst R, Chauhan M, Weir KA. Oral feeding for infants and children receiving nasal continuous positive airway pressure and high-flow nasal cannula respiratory supports: a survey of practice. Dysphagia 2020; 35: 443–454.
6. Leder SB, Siner JM, Bizzarro MJ, McGinley BM, Lefton-Greif MA. Oral alimentation in neonatal and adult populations requiring high-flow oxygen via nasal cannula. Dysphagia 2016; 31: 154–159.
7. Dalgleish SR, Kostecky LL, Blachly N. Eating in "SINC. Neonatal Network 2016; 35: 217–227.
8. Ferrara L, Bidiwala A, Sher I, et al. Effect of nasal continuous positive airway pressure on the pharyngeal swallow in neonates. J Perinatol 2017; 37: 398–403.
9. Dysart K, Miller TL, Wolfson MR, Shaffer TH. Research in high flow therapy: mechanisms of action. Resp Med 2009; 103: 1400–1405.
10. Sreenan C, Lemke RP, Hudson-Mason A, Osiovich H. High-flow nasal cannulae in the management of apnea of prematurity: a comparison with conventional nasal continuous positive airway pressure. Pediatrics 2001; 107: 1081–1083.
11. Raminick J, Desai H. High flow oxygen therapy and the pressure to feed infants with acute respiratory illness. perspectives of the ASHA special interest groups, 2020; 5: 1006–1010.
12. Coker-Bolt P, Jarrard C, Woodard F, Merrill P. The effects of oral motor stimulation on feeding behaviors of infants born with univentricle anatomy. J Pediatr Nurs 2013; 28: 64–71.
13. Jakaitis BM, Denning PW. Human breast milk and the gastrointestinal innate immune system. Clin Perinatol 2014; 41: 423–435.
14. Davis JA, Baumgartel K, Morowitz MJ, Giangrasso V, Demirci JR. The role of human milk in decreasing necrotizing enterocolitis through modulation of the infant gut microbiome: a scoping review. J Hum Lact 2020; 36: 647–656.
15. Medoff-Cooper B, Naim M, Torowicz D, Mott A. Feeding, growth, and nutrition in children with congenitally malformed hearts. Cardiol Young 2010; 20: 149–153.
16. Lee J, Kim HS, Jung YH, et al. Oropharyngeal colostrum administration in extremely premature infants: an RCT. Pediatrics 2015; 135: e357–e366.
17. Patel AL, Kim JH. Human milk and necrotizing enterocolitis. In: Saunders WB (eds). Seminars in Pediatric Surgery. vol. 27, 2018: 34–38.
18. Pados BF, Davitt ES. Pathophysiology of gastroesophageal reflux disease in infants and nonpharmacologic strategies for symptom management. Nurs Women's Health 2020; 24: 101–114.
19. Indramohan G, Pedigo TP, Rostoker N, Cambare M, Grogan T, Federman MD. Identification of risk factors for poor feeding in infants with congenital heart disease and a novel approach to improve oral feeding. J Pediatr Nurs 2017; 1: 149–154.
20. Steltzer M, Rudd N, Pick B. Nutrition care for newborns with congenital heart disease. Clin Perinatol 2005; 32: 1017–1030.
21. Weesner KM, Rosenthal A. Gastroesophageal reflux in association with congenital heart disease. Clin Pediatr 1983; 22: 424–426.
22. Esposito C, Roberti A, Turrà F, et al. Management of gastroesophageal reflux disease in pediatric patients: a literature review. Pediatric Health Med Ther 2015; 6: 1–8.
23. Hasenstab KA, Jadcherla SR. Gastroesophageal reflux disease in the neonatal intensive care unit neonate: controversies, current understanding, and future directions. Clin Perinatol 2020; 47: 243–263.
24. Malkar MB, Jadcherla S. Neuromotor mechanisms of pharyngoesophageal motility in dysphagic infants with congenital heart disease. Pediatr Res 2014; 76: 190–196.
25. Sdravou K, Emmanouilidou-Fotoulaki E, Mitakidou MR, Printza A, Evangeliou A, Fotoulaki M. Children with diseases of the upper gastrointestinal tract are more likely to develop feeding problems. Ann Gastroenterol 2019; 32: 217–233.
26. Rosen R, Vandenplas Y, Singendonk M, et al. Pediatric Gastroesophageal Reflux Clinical Practice Guidelines: Joint Recommendations of the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition and the European Society for Pediatric Gastroenterology, Hepatology, and Nutrition. J Pediatr Gastroenterol Nutr 2018 Mar; 66: 516–554.
27. Corvaglia L, Martini S, Aceti A, Arcuri S, Rossini R, Faldella G. Nonpharmacological management of gastroesophageal reflux in preterm infants. Biomed Res Int 2013; 2013: 141967.
28. Loots C, Kritas S, van Wijk M, et al. Body positioning and medical therapy for infantile gastroesophageal reflux symptoms. J Pediatr Gastroenterol Nutr 2014; 59: 237–243.
29. Martinez EE, Douglas K, Nurko S, Mehta NM. Gastric dysmotility in critically ill children: pathophysiology, diagnosis, and management. Pediatr Crit Care Med 2015; 16: 828–836.
30. Diego MA, Field T, Hernandez-Reif M, Deeds O, Ascencio A, Begert G. Preterm infant massage elicits consistent increases in vagal activity and gastric motility that are associated with greater weight gain. Acta Paediatr 2007; 96: 1588–1591.
31. Green Corkins K. Nutrition-focused physical examination in pediatric patients. Nutr Clin Pract 2015; 30: 203–209.
32. Mitchell IM, Logan RW, Pollock JC, Jamieson MP. Nutritional status of children with congenital heart disease. Br Heart J 1995; 73: 277–283.
33. de Onis M, Habicht JP. Anthropometric reference data for international use: recommendations from a World Health Organization Expert Committee. Am J Clin Nutr 1996; 64: 650–658.
34. Kalra R, Vohra R, Negi M, et al. Feasibility of initiating early enteral nutrition after congenital heart surgery in neonates and infants. Clin Nutr ESPEN 2018; 25: 100–102.
35. Furlong-Dillard J, Neary A, Marietta J, et al. Evaluating the impact of a feeding protocol in neonates before and after biventricular cardiac surgery. Pediatr Qual Saf 2018; 3: e080.
36. Toms R, Jackson KW, Dabal RJ, Reebals CH, Alten JA. Preoperative trophic feeds in neonates with hypoplastic left heart syndrome. Congenit Heart Dis 2015; 10: 36–42.
37. Martini S, Beghetti I, Annunziata M, et al. Enteral nutrition in term infants with congenital heart disease: knowledge gaps and future directions to improve clinical practice. Nutrients 2021; 13: 932.
38. Lisanti AJ, Savoca M, Gaynor JW, et al. Standardized feeding approach mitigates weight loss in infants with congenital heart disease. J Pediatr 2021; 231: 124–130.e1.
39. Chinawa AT, Chinawa JM, Duru CO, Chukwu BF, Obumneme-Anyim I. Assessment of nutritional status of children with congenital heart disease: a comparative study. Front Nutr 2021; 8: 644030.
40. Kelleher DK, Laussen P, Teixeira-Pinto A, Duggan C. Growth and correlates of nutritional status among infants with hypoplastic left heart syndrome (HLHS) after stage 1 Norwood procedure. Nutrition. 2006; 22: 237–244.
41. McHoney M, Eaton S, Pierro A. Metabolic response to surgery in infants and children. Eur J Pediatr Surg 2009; 19: 275–285. DOI 10.1055/s-0029-1241192.

https://doi.org/10.1017/S1047951122004024 Published online by Cambridge University Press

42. Neumann L, Springer T, Nieschke K, Kostelka M, Dähnert I. ChyloBEST: chylothorax in infants and nutrition with low-fat breast milk. Pediatr Cardiol 2020; 41: 108–113.
43. Tsintoni A, Dimitriou G, Karatza AA. Nutrition of neonates with congenital heart disease: existing evidence, conflicts and concerns. J Matern Fetal Neonatal Med 2020; 33: 2487–2492.
44. Thoyre SM, Shaker CS, Pridham KF. The early feeding skills assessment for preterm infants. Neonatal Netw 2005; 24: 7–16.
45. Palmer MM, Crawley K, Blanco IA. Neonatal oral-motor assessment scale: a reliability study. J Perinatol 1993; 13: 28–35.
46. Pados BF, Thoyre SM, Estrem HH, Park J, McComish C. Factor structure and psychometric properties of the neonatal eating assessment tool—bottle-feeding (NeoEAT—Bottle-Feeding). Adv Neonat Care 2018; 18: 232–242.
47. Pineda B. The Neonatal Eating Outcome (NEO) assessment: a new developmental feeding assessment for preterm infants in the NICU. Am J Occup Ther 2019; 4: 1–7311500065p1.
48. Pados BF, Park J, Estrem H, Awotwi A. Assessment tools for evaluation of oral feeding in infants younger than 6 months. Adv Neonatal Care 2016; 16: 143–150.
49. Pados BF, Estrem HH, Thoyre SM, Park J, McComish C. The neonatal eating assessment tool: development and content validation. Neonatal Network 2017; 36: 359–367.
50. Howe TH, Lin KC, Fu CP, Su CT, Hsieh CL. A review of psychometric properties of feeding assessment tools used in neonates. J Obstet Gynecol Neonatal Nurs 2008; 37: 338–349.
51. Bickell M, Barton C, Dow K, Fucile S. A systematic review of clinical and psychometric properties of infant oral motor feeding assessments. Dev Neurorehabil 2018; 21: 351–361.
52. Lau C, Smith EO. A novel approach to assess oral feeding skills of preterm infants. Neonatology. 2011; 100: 64–70.
53. Ehrmann DE, Mulvahill M, Harendt S, et al. Toward standardization of care: the feeding readiness assessment after congenital cardiac surgery. Congenit Heart Dis 2018; 13: 31–37.
54. Park J, Pados BF, Thoyre SM. Systematic review: what is the evidence for the side-lying position for feeding preterm infants? Adv Neonatal Care 2018; 18: 285–294.
55. Thoyre S, Park J, Pados B, Hubbard C. Developing a co-regulated, cue-based feeding practice: the critical role of assessment and reflection. J Neonatal Nurs 2013; 19: 139–148.
56. Daley HK, Kennedy CM. Meta analysis: effects of interventions on premature infants feeding. J Perinat Neonatal Nurs 2000; 14: 62–77.
57. Pados BF, Park J, Thoyre SM, Estrem H, Nix WB. Milk flow rates from bottle nipples used after hospital discharge. MCN Am J Matern Child Nurs 2016; 41: 237–243.
58. al-Sayed LE, Schrank WI, Thach BT. Ventilatory sparing strategies and swallowing pattern during bottle feeding in human infants. J Appl Physiol 1994; 77: 78–83.
59. Pados BF, Park J, Dodrill P. Know the flow: milk flow rates from bottle nipples used in the hospital and after discharge. Adv Neonatal Care 2019; 19: 32–41.
60. Elgersma KM, McKechnie AC, Gallagher T, Trebilcock AL, Pridham KF, Spatz DL. Feeding infants with complex congenital heart disease: a modified Delphi survey to examine potential research and practice gaps. Cardiol Young 2021; 31: 577–588.
61. Ingram J, Johnson D, Copeland M, Churchill C, Taylor H. The development of a new breast feeding assessment tool and the relationship with breast feeding self-efficacy. Midwifery 2015; 31: 132–137.
62. Jensen D, Wallace S, Kelsay P. LATCH: a breastfeeding charting system and documentation tool. J Obstet Gynecol Neonatal Nurs 1994; 23: 27–32.
63. Sowjanya SVNS, Venugopalan L. LATCH score as a predictor of exclusive breastfeeding at 6 weeks postpartum: a prospective cohort study. Breastfeed Med 2018; 13: 444–449.
64. Pados BF, Thoyre SM, Galer K. Neonatal eating assessment tool-mixed breastfeeding and bottle-feeding (NeoEAT-mixed feeding): factor analysis and psychometric properties. Matern Health Neonatol Perinatol 2019; 5: 1–15.
65. Davis JA, Spatz DL. Human milk and infants with congenital heart disease: a summary of current literature supporting the provision of human milk and breastfeeding. Adv Neonatal Care 2019; 19: 212–218.
66. Combs VL, Marino BL. A comparison of growth patterns in breast and bottle-fed infants with congenital heart disease. Pediatr Nurs 1993; 19: 175–179.
67. Goldfield EC, Richardson MJ, Lee KG, Margetts S. Coordination of sucking, swallowing, and breathing and oxygen saturation during early infant breast-feeding and bottle-feeding. Pediatr Res 2006; 60: 450–455.
68. Medoff-Cooper B, Shults J, Kaplan J. Sucking behavior of preterm neonates as a predictor of developmental outcomes. J Dev Behav Pediatr 2009; 30: 16–22.
69. Sharma A. Efficacy of early skin-to-skin contact on the rate of exclusive breastfeeding in term neonates: a randomized controlled trial. Afr Health Sci 2016; 16: 790–797.
70. Harrison TM, Ludington-Hoe S. A case study of infant physiologic response to skin-to-skin contact after surgery for complex congenital heart disease. J Cardiovasc Nurs 2015; 30: 506–516.
71. Lisanti AJ, Demianczyk AC, Costarino A, et al. Skin-to-skin care is associated with reduced stress, anxiety, and salivary cortisol and improved attachment for mothers of infants with critical congenital heart disease. J Obstet Gynecol Neonatal Nurs 2021; 50: 40–54.
72. Kaya V, Aytekin A. Effects of pacifier use on transition to full breastfeeding and sucking skills in preterm infants: a randomised controlled trial. J Clin Nurs 2017; 26: 2055–2063.
73. Say B, Simsek GK, Canpolat FE, Oguz SS. Effects of pacifier use on transition time from gavage to breastfeeding in preterm infants: a randomized controlled trial. Breastfeed Med 2018; 13: 433–437.
74. Jadcherla SR, Khot T, Moore R, Malkar M, Gulati IK, Slaughter JL. Feeding methods at discharge predict long-term feeding and neurodevelopmental outcomes in preterm infants referred for gastrostomy evaluation. J Pediatr 2017; 181: 125–130.e1.
75. Pham V, Connelly D, Wei JL, Sykes KJ, O'Brien J. Vocal cord paralysis and dysphagia after aortic arch reconstruction and Norwood procedure. Otolaryngol Head Neck Surg 2014; 150: 827–833.
76. Rogers B, Arvedson J. Assessment of infant oral sensorimotor and swallowing function. Ment Retard Dev Disabil Res Rev. 2005; 11: 74–82.
77. Pourmoghadam KK, DeCampli WM, Ruzmetov M, et al. Recurrent laryngeal nerve injury and swallowing dysfunction in neonatal aortic arch repair. Ann Thorac Surg 2017; 104: 1611–1618.
78. Ryan MA, Upchurch PA, Senekki-Florent P. Neonatal vocal fold paralysis. Neoreviews 2020; 21: e308–e322.
79. Benjamin JR, Smith PB, Cotten CM, Jaggers J, Goldstein RF, Malcolm WF. Long-term morbidities associated with vocal cord paralysis after surgical closure of a patent ductus arteriosus in extremely low birth weight infants. J Perinatol 2010; 30: 408–413.
80. Pham V, Connelly D, Wei JL, Sykes KJ, O'Brien J. Vocal cord paralysis and Dysphagia after aortic arch reconstruction and Norwood procedure. Otolaryngol Head Neck Surg 2014; 150: 827–833.
81. McGrattan KE, McGhee H, DeToma A, et al. Dysphagia in infants with single ventricle anatomy following stage 1 palliation: physiologic correlates and response to treatment. Congenit Heart Dis 2017; 12: 382–388.
82. Raulston JEB, Smood B, Moellinger A, et al. Aspiration after congenital heart surgery. Pediatr Cardiol 2019; 40: 1296–1303.
83. Karsch E, Irving SY, Aylward BS, Mahle WT. The prevalence and effects of aspiration among neonates at the time of discharge. Cardiol Young 2017; 27: 1241–1247.
84. Arvedson JC. Assessment of pediatric dysphagia and feeding disorders: clinical and instrumental approaches. Dev Disabil Res Rev. 2008; 14: 118–127.
85. Schroeder JW, Willette S, Molinaro LH. Fiberoptic endoscopic evaluation of swallowing: Assessing dysphagia in the breastfeeding patient. In Pediatric Dysphagia 2018. Springer, Cham, 93–99.
86. Duncan DR, Larson K, Rosen RL. Clinical aspects of thickeners for pediatric gastroesophageal reflux and oropharyngeal dysphagia. Curr Gastroenterol Rep 2019; 21: 30.

https://doi.org/10.1017/S1047951122004024 Published online by Cambridge University Press

87. Dion S, Duivestein JA, St Pierre A, Harris SR. Use of thickened liquids to manage feeding difficulties in infants: a pilot survey of practice patterns in canadian pediatric centers. Dysphagia 2015; 30: 457–472.
88. Steele CM, Alsanei WA, Ayanikalath S, et al. The influence of food texture and liquid consistency modification on swallowing physiology and function: a systematic review. Dysphagia 2015; 30: 2–26.
89. Goldfield EC, Smith V, Buonomo C, Perez J, Larson K. Preterm infant swallowing of thin and nectar-thick liquids: changes in lingual-palatal coordination and relation to bolus transit. Dysphagia 2013; 28: 234–244.
90. Newman R, Vilardell N, Clavé P, Speyer R. Effect of bolus viscosity on the safety and efficacy of swallowing and the kinematics of the swallow response in patients with oropharyngeal dysphagia: white paper by the european society for swallowing disorders (ESSD). Dysphagia 2016; 31: 232–249.
91. Almeida MB, Almeida JA, Moreira ME, Novak FR. Adequacy of human milk viscosity to respond to infants with dysphagia: experimental study. J Appl Oral Sci 2011; 19: 554–559.
92. Beal J, Silverman B, Bellant J, Young TE, Klontz K. Late onset necrotizing enterocolitis in infants following use of a xanthan gum-containing thickening agent. J Pediatr 2012; 161: 354–356.
93. McCallum S. Addressing nutrient density in the context of the use of thickened liquids in dysphagia treatment. ICAN Infant Child Adolesc Nutr 2011; 3: 351–360.
94. Wolter NE, Hernandez K, Irace AL, et al. A systematic process for weaning children with aspiration from thickened fluids. JAMA Otolaryngol 2018; 144: 51–56.
95. Madhoun LL, Siler-Wurst KK, Sitaram S, Jadcherla SR. Feed-thickening practices in NICUs in the current era: variability in prescription and implementation patterns. J Neonatal Nurs. 2015; 21: 255–262.
96. Limperopoulos C, Majnemer A, Shevell MI, Rosenblatt B, Rohlicek C, Tchervenkov C. Neurologic status of newborns with congenital heart defects before open heart surgery. Pediatrics 1999; 103: 402–408.
97. Limperopoulos C, Majnemer A, Shevell MI, Rosenblatt B, Rohlicek C, Tchervenkov C. Neurodevelopmental status of newborns and infants with congenital heart defects before and after open heart surgery. J Pediatr 2000; 137: 638–645.
98. Donofrio MT, Massaro AN. Impact of congenital heart disease on brain development and neurodevelopmental outcome. Int J Pediatr 2010; 2010: 359–390.
99. Butler SC, Sadhwani A, Stopp C, et al. Neurodevelopmental assessment of infants with congenital heart disease in the early postoperative period. Congenit Heart Dis. 2019; 14: 236–245.
100. Butler SC, Sadhwani A, Rofeberg V, et al. Neurological features in infants with congenital heart disease. Dev Med Child Neurol 2021
101. Gakenheimer-Smith L, Glotzbach K, Ou Z, et al. The impact of neurobehavior on feeding outcomes in neonates with congenital heart disease. J Pediatr 2019; 214: 71–78.
102. Desai H, Lim A. Neurodevelopmental intervention strategies to improve oral feeding skills in infants with congenital heart defects. ASHAwire Perspect 2019; 4: 1492–1497.
103. Brazelton TB, Nugent JK, Lester BM. Neonatal behavioral assessment scale. In: Osofsky JD (eds). Handbook of Infant Development, 2nd. John Wiley & Sons, New York, 1987: 780–817.
104. Nugent JK, Keefer CH, Minear S, Johnson LC, Blanchard Y. The newborn behavioral observations (NBO) system handbook. Paul H Brookes Publishing, Baltimore, MD, USA, 2007.
105. Als H, Lester BM, Tronick EZ, Brazelton TB. Toward a research instrument for the assessment of preterm infants' behavior (APIB). In Theory and research in behavioral pediatrics. Springer, Boston, MA, 1982: 35–132.
106. Lester BM, Tronick EZ, Brazelton TB. The neonatal intensive care unit network neurobehavioral scale procedures. Pediatrics 2004; 113: 641–667.
107. Ross ES, Philbin MK. Supporting oral feeding in fragile infants: an evidence-based method for quality bottle-feedings of preterm, ill, and fragile infants. J Perinat Neonatal Nurs 2011; 25: 349–357.
108. Medoff-Cooper B, Rankin K, Li Z, Liu L, White-Traut R. Multisensory intervention for preterm infants improves sucking organization. Adv Neonatal Care 2015; 15: 142–149.
109. White-Traut RC, Nelson MN, Silvestri JM, et al. Effect of auditory, tactile, visual, and vestibular intervention on length of stay, alertness, and feeding progression in preterm infants. Dev Med Child Neurol 2002; 44: 91–97.
110. Lisanti AJ, Vittner D, Medoff-Cooper B, Fogel J, Wernovsky G, Butler S. Individualized family centered developmental care: an essential model to address the unique needs of infants with congenital heart disease. J Cardiovasc Nurs 2019; 34: 85–93.
111. Als H. Program Guide - Newborn Individualized Developmental Care and Assessment Program (NIDCAP): An Education and Training Program for Health Care Professionals. Copyright, NIDCAP Federation International, Boston, 1986. Unpublished Manuscript. Rev 2009,
112. Als H, Duffy FH, McAnulty GB, et al. Early experience alters brain function and structure. Pediatrics 2004; 113: 846–857.
113. Butler SC, Huyler K, Kaza A, Rachwal C. Filling a significant gap in the cardiac ICU: implementation of individualised developmental care. Cardiol Young 2017; 27: 1797–1806.
114. Lisanti AJ, Allen LR, Kelly L, Medoff-Cooper B. Maternal stress and anxiety in the Pediatric Cardiac Intensive Care Unit. Am J Crit Care 2017; 26: 118–125. DOI 10.4037/ajcc2017266.
115. Gramszlo C, Karpyn A, Demianczyk AC, et al. Parent perspectives on family-based psychosocial interventions for congenital heart disease. J Pediatr 2020; 216: 51–57.
116. Marino BS, Lipkin PH, Newburger JW, et al. Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management: a scientific statement from the American Heart Association. Circulation 2012; 126: 1143–1172.
117. Sharp WG, Volkert VM, Scahill L, McCracken CE, McElhanon B. A systematic review and meta-analysis of intensive multidisciplinary intervention for pediatric feeding disorders: how standard is the standard of care? J Pediatr 2017; 181: 116–124.
118. Slater N, Spader M, Fridgen J, Horsley M, Davis M, Griffin KH. Weaning from a feeding tube in children with congenital heart disease: a review of the literature. Prog Pediatr Cardiol 2021; 62: 101406.
119. Taylor S, Purdy SC, Jackson B, Phillips K, Virues-Ortega J. Evaluation of a home-based behavioral treatment model for children with tube dependency. J Pediatr Psychol 2019; 44: 656–668.

https://doi.org/10.1017/S1047951122004024 Published online by Cambridge University Press