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Original Article

Innovative Strategies for Feeding and Nutrition in Infants with Congenitally Malformed Hearts

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As the success of the surgical approach to palliation and repair of neonates with congenitally malformed hearts has improved, so has the number of these infants who present with failure of growth.[1] Infants with congenitally malformed hearts are usually born at full term, and within the normal range for weight. Nutritional issues often emerge shortly after surgery, and persist throughout the first year or years of life. Failure of growth in itself is associated with an array of health problems, and is directly related to challenges encountered with intake of substrates for energy. What remains unclear is why some infants are able to feed orally, while others have difficulty.[2] Of all infants with complex malformed hearts, it is those who have passed through the first stage of palliation for univentricular physiology who are most at risk for developing poor feeding skills, having less than an adequate nutritional intake, and failing to grow, with over half of these infants struggling to attain and maintain a weight that is 2 standard deviations below the mean.[3] Most alarming is the finding that, during the first months following surgery for correction of congenital cardiac disease, a strong association exists between a decrease in weight for age and mortality during the first year of life.[4]

Feeding, the most complex task the infant must perform, requires coordination and integration of motor and sensory pathways of the oropharynx. Skills in feeding, and behaviors which are present at birth, are useful as a means of evaluating the ability of the infant to achieve an adequate nutritional state and growth. Abnormalities in swallowing in these infants include variability in sucking, an uncoordinated suck, swallow and breathing, and oral transit time.[5,6] Often the feeding experience is overlooked. That experience, however, along with neurological maturation, are key factors to be considered in the ability of an infant to attain optimal nutritional intake.[7,8] Poor skills in feeding, and dysfunctional swallowing, can directly affect the ability to feed, and hence for the infant to meet nutritional requirements.

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Scope of the Problem

From our work, we have found that almost half of infants discharged home after the first stage of palliation for hypoplastic left heart syndrome were receiving full feeds, either from the breast or by bottle. The remainder, just over half of the cohort, required nutritional support, with either supplementation of breast or bottle feeding by nasogastric tube, full feeds through the nasogastric tube, or feeding through surgically implanted tubes (Fig. 1). Despite the difference in the mode of feeding at the time of discharge from hospital, there was no difference in the z-scores for weight between the groups at the time of discharge.[3] Whether the infant was discharged on oral or supported feeds, mothers describe dysfunctional feeding to include gagging, choking, behaviours to avoid oral feeding, and poor gain in weight in many infants. Multiple

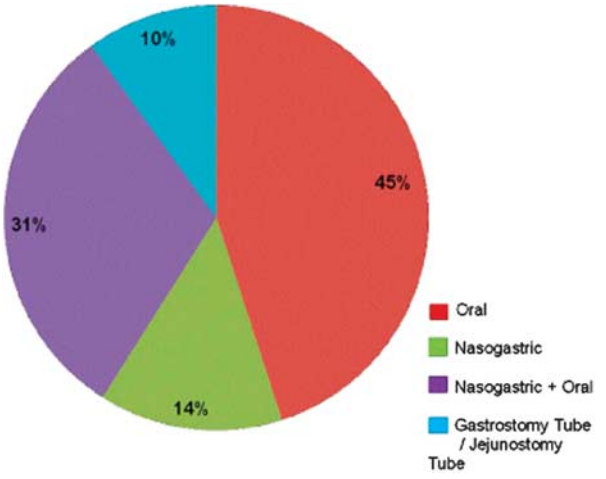

Figure 1.
The mode of feeding at the time of discharge from hospital for infants after the first stage of palliation. N = 61.

factors have been implicated as the underlying source of the dysfunction and poor gain in weight so often seen in these infants. These factors include immature cerebral development, dysphagia, which may be secondary to the surgical approach, intraoperative support times, dysfunctional vocal cords, inadequate caloric intake, and/or postoperative gastrointestinal dysfunction.[2,9–11]

Research on dysfunctional feeding

Difficulties with oral feeding are defined as those present in an infant who is not entirely orally fed by bottle or breast at the time of discharge from hospital.[2] In a retrospective study of 72 infants who were orally feeding at discharge, and 29 who were not, multivariate logistic regression analysis revealed injury to the vocal cords, with an odds ratio of 11.80, the length of postoperative intubation, with an odds ratio of 1.1 per day, and weight at surgery, with an odds ratio of 0.34, all predicting the failure to feed orally at discharge.[2] Up to one-fifth of infants have been reported to be at risk of dysphasia, or dysfunctional swallowing, after open heart surgery.[12] The risk factors for dysphasia include the type of surgical repair, the length of postoperative intubation, and use of a transoesophageal echocardiogic probe[12]. Following the Norwood procedure, dysfunctional swallowing has been reported in up to half the survivors,[5] due to intraoperative manipulation of the recurrent laryngeal nerve increasing the potential for neural damage. These studies support the notion that the complex process of feeding and dysfunctional feeding postoperatively for infants with congenitally malformed hearts is a multifactorial effect, resulting from a combination of factors that may all contribute to the efficiency of the infant to feed orally and establish optimal nutritional intake and growth.[13]

The presence of congenital cardiac disease, especially those defects producing a significant runoff from the systemic to the pulmonary arterial systems, is believed to increase the risk of developing necrotizing enterocolitis, and may be directly related to mesenteric ischaemia.[11,14,15] Despite this concern, McElhinney and colleagues[14] failed to find any relationship between feeding history, the type of feeding, use of an indwelling umbilical catheter or cardiac catheterization, and the incidence of necrotizing enterocolitis. Of note, most infants recover from the diagnosis or suspicion of necrotizing enterocolitis without surgery. At the Duke Children's Hospital, a specific protocol for feeding is used to decrease the incidence of necrotizing enterocolitis, and improve the overall rates of oral feeding. Despite the assertion by some that the history of feeding is not associated with the onset of necrotizing enterocolitis, results using the Duke protocol are promising.[16] Early monitoring, and response to the presenting symptoms associated with necrotizing enterocolitis, may decrease the length of time of interruptions between feeds, and the progress towards successful oral feedings. In addition to necrotizing enterocolitis, gastroesophageal reflux is also seen in infants with congenitally malformed hearts, and may be more prevalent in infants with functionally univentricular lesions.[17]

An inadequate intake of substrates providing energy is of considerable importance when considering the nutritional state in the period between the surgical procedure and discharge from hospital, and is thought to be the predominant cause of failure to grow.[17] The target intake for the infant after the surgical procedure is between 120 and 150 kcal/kg per day, with an expected gain in weight of 20 to 30 grams per day. It has been suggested that infants with haemodynamically significant lesions within the heart require more nutritional support to sustain growth, with some requiring as much as 175 to 189 kcal/kg/day for catch-up growth.[18] In a retrospective review of 100 neonates admitted to the cardiac surgical unit at Children's Hospital of Philadelphia, the median nutritional intake was found to be 93 kcal/kg/day, with a range from 43 to 142 kcal/kg/day.[19] An intake of 100 kcal/kg/day was achieved only half of the time, and an intake of 120 kcal/kg was achieved only one-fifth of the time. Significantly, feedings were discontinued, or interrupted for procedures, on three-tenths of the total feeding days.[19] In addition to planned cardiac or non-cardiac procedures, many

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reasons were identified as to why the feedings were interrupted, including irritability of the infant, gastrointestinal issues such as emesis and abdominal distention, fluid restrictions, and deterioration of the clinical state.[19] Other impediments to the delivery of nutrition in infants at high-risk include mechanical challenges, such as insertion and maintenance of orogastric or nasogastric feeding tubes, and feeding intolerance.

Recent work on cerebral development and function in infants with complexly malformed hearts may lend itself to a more thorough understanding of the problems with feeding. Periventricular leukomalacia, a form of cerebral injury often seen in premature infants, has been hypothesized to be a causative factor predisposing infants with congenitally malformed hearts to the susceptibility for neurologic insults in the preoperative, intraoperative, and post-operative periods. Infants with hypoplastic left heart syndrome are known to have smaller and structurally less mature brains than would be expected for a full term infant.[9] Such periventricular leukomalacia has been associated with problems in feeding and growth failure in both preterm and full term infants, and may be one of the many factors contributing to risk of poor feeding and subsequent failure to grow.[20]

Potential Feeding Strategies

While timely nutritional intervention is necessary to maintain an adequate nutritional state, finding strategies that enhance feeding skills, and ensure an adequate nutritional intake, has eluded both professionals working in paediatric cardiology and their colleagues working in primary care. Many paediatric cardiac centers are striving to develop a protocol for feeding after cardiac surgical procedures that is efficient and effective in ensuring an adequate intake of substrates for energy that fosters a gain in weight, and allows for an objective assessment of the skills with feeding and progress achieved by the infant. Protocols are being considered, or designed, with a focus on those infants with the most difficult problems with feeding, most often those infants who have undergone the first stage of palliation for hypoplastic left heart syndrome, or who have complex malformations with a ductal-dependent systemic circulation resulting in postoperative functionally univentricular physiology. In our sample of 61 infants, about half had hypoplasia of the left heart, while the other half had an array of complex malformations that required the first stage of the palliative procedure.[3]

A systematic approach is needed, inclusive of physical and behavioural signals, so as to provide a clear picture of the process and progress of the ability of the individual infant to feed. In addition to understanding the physiologic challenges the infant must overcome, there is a developmental component to be considered, along with the responsibilities of the providers of care, which must be employed to assist the neonate to achieve successful feeding after a cardiac surgical procedure. Criterions at the time of discharge from hospital must include their physiologic stability, their established skills in feeding, and evidence of a sustained and progressive gain in weight.[21]

Assessment of the behaviour of the infant is an integral component to be considered when making decisions relating to oral feeding. Successful feeding is suggested to be an acknowledged developmental milestone for infants.[21] In the case of the infant who has undergone surgical correction of complex congenital cardiac disease, the developmental process involves the ability of the infant to integrate new demands while maintaining hemodynamic stability. The goal of facilitating skills in feeding includes progression from stability while being held, to sucking on a pacifier, and ultimately feeding either from a bottle or the breast. Early pacing of the time and frequency of feeding, along with recognition of the cues of the stability of the physiological, motor, and behavioural state, will contribute to more efficient feeding sessions.

To date, we are aware of 2 published protocols that address the issues of feeding for high-risk infants, albeit that only one of the 2 specifically addresses the challenges for the infant following cardiac surgery. The Regional Neonatal Oral Feeding Protocol developed by the Calgary Health Region can be adapted for the cardiac neonatal population.[6] The protocol was developed as a guideline to be used by families and providers of healthcare for the introduction and management of oral feeding for high-risk neonates and infants. Its goals, which are based on both previously published material and the clinical expertise of the interdisciplinary team, are to create positive experiences during feeding, while assisting the infants to achieve full oral intake, and preventing the development of aversive oral behaviours.[6] There are 4 basic premises of the protocol.

- feeding is an active social interaction between an infant and the caregiver,
- development of oral feeding is a process with identifiable stages,
- stages are used to plan appropriate feeding experiences which foster physiologic stability,
- movement between stages may be bi-directional.

The stages as outlined include non-nutritive sucking, minimum oral feeding, moderate oral feeding, which may include both oral and nasal gastric support, and, finally, full oral feeding. The protocol provides a

detailed description of the characteristics of the infants, the interventions, and suggestions for referrals for each feeding stage which are applicable to those fed either by the bottle or breast, acknowledging that consultation on lactation further enhances the success of breast feeding in high risk infants. Using an assessment tool to document each feeding is a critical component of the continuity and progress of a consistent plan. The Calgary protocol includes an assessment tool that could be adapted for use in the infant after cardiac surgery, albeit that, in its current form, it is clearly based on the progression of feeding for infants born prior to term.

The Enteral Feeding Algorithm of the Boston Cardiovascular Program was developed to address the issues of the variability in the initiation and delivery of nutrition, and the optimization of intake of substrates for energy in high-risk infants.[11] The process described in the Boston algorithm includes initiation and advancement of enteral feedings, with specific assessment of gastric residuals, abdominal girth, and signs of gastrointestinal feeding intolerance.[11] Through use of the protocol, the Boston centre has been able to achieve adequate intake of substrates for energy, and decrease the use of parenteral nutrition for infants following the first stage of palliation. There is still, however, the challenge of gain in weight at discharge from hospital, which initiation and adherence to the protocol did not overcome. Additionally, the protocol does not specifically address the challenges of oral feeding in this population of high-risk infants.

Another strategy to address poor gain in weight by neonates with complexly malformed hearts is to introduce feedings earlier in the postoperative course, and rapidly increase the caloric density and volume of enteral feeding[22,23]. This approach emphasizes the increased intake of substrates for energy and nutrition through a systematized accelerated increase in calories. Early assessments of this approach show promising results, albeit that more investigation is necessary to substantiate its use.

Given the urgency to address difficulties with feeding in this population, several institutions are in the process of testing protocols and algorithms based on developmental principals parallel to those outlined in the Calgary Protocol, with more specificity for the cardiac neonatal population. Unfortunately, beyond what we have presented here, none of these emerging protocols have been published beyond abstracts presented at professional meetings.

Additional Strategies

Assessment of Feeding

From our ongoing work on the behaviours observed during feeding of infants with complexly malformed hearts, and as we have already emphasized, it is the infants surviving the first stage of palliation who appear to be at the greatest risk of inadequate feeding and failure to grow.[3] The decision to begin oral feeding, whether it is by breast, bottle, full, or partial nasogastric feedings, is generally made by the medical and nursing team through evaluating the physiologic stability, with little attention given to the developmental cues for success with feeding and gain in weight. While increase in weight is an objective measure of energy balance, success of feeding is more difficult to quantify. One approach objectively to measure such success would be to assess the nutritive sucking microstructure, a technique developed for neonates and young infants at high risk.[24,25] The paradigm of maturation over time, which applied to preterm infants, where infants showed more organized feeding with increasing post-menstrual age, did not hold true for the full term post-surgical neonates. Rather, a wider range of feeding skills was observed. For the most part, nonetheless, we are able to classify infants as demonstrating either organized or disorganized patterns of sucking (Figs 2 and 3). The difference between the two categories of sucking is in the ability of the infant to generate a cluster, or burst, of sucks with short pauses, as compared to an infant with short bursts of less than 5 sucks, and longer pauses between bursts. While this tool currently remains a research method, there is promise for its use clinically as a component of the evaluation of oral feeding.

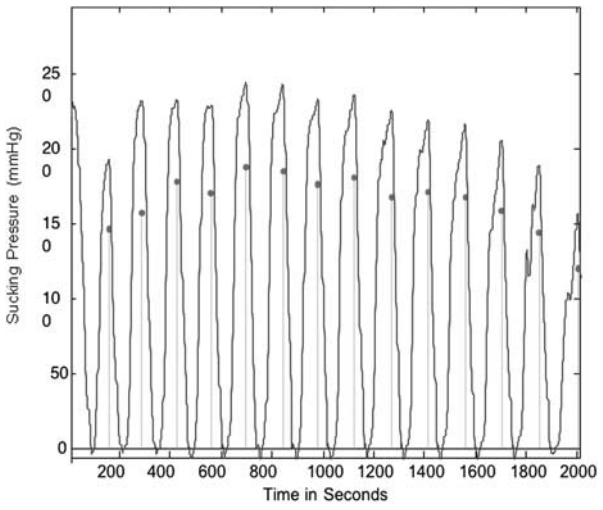

Figure 2.
The trace shows an organized pattern of sucking.

Developmental Care Bundles/Nursing-Medical Care Bundles

In addition to assessment of the physiologic, neurologic, developmental, and behavioural state

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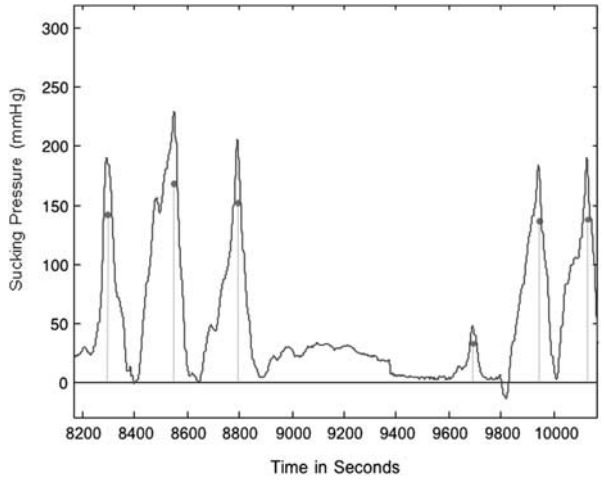

Figure 3.
In contrast to the pattern shown in Figure 2, this infant has a disorganized pattern of sucking.

of the infant, success in intake of substrates for energy to foster the gain in weight required by this population must include the development of nursing-medical care bundles specifically aimed at minimizing interruptions of feeding, and improving outcomes as evidenced by an adequate intake of substrates for energy and gain in weight. Following surgical intervention, there is always the necessity of interrupting feeding. Vigilance can be employed, nonetheless, to bundle together invasive procedures, off-unit diagnostic tests, and examinations that necessitate temporary termination of nutritional intake. Along with planned cessation of feeding, a plan for recommencement of the feeding specific to time and volume should be determined, with a detailed outline of the assessment of those parameters that would prohibit the resumption of feedings.

Included in the care bundles that address the challenges to feeding of infants with complex congenital cardiac disease following the first stage of palliation are the responsibilities of the caregivers that can aid the infant in successful feeding. The necessary skills required by the infant to attain success in feeding, inclusive of their interaction with the immediate environment and the caregiver, add an additional dimension to an already complex process, and one which is difficult to quantify. Limiting and maintaining consistent providers of care, such as in primary nursing models, facilitates recognition and documentation of the cues provided by the infants that identify their readiness for, and ability to tolerate, oral feeding. Providing the appropriate nipple, and recognizing the proficiency of the infant with coordination of suck, swallow, breathing and volume transfer as they maintain physiologic stability, is an essential component to the progress of feeding achieved by the individual infant, and their ultimate success in feeding. Appropriate holding, swaddling, or positioning during feedings, recognizing the optimal awake-sleep infant state, and minimizing environmental stimulus during feeding, are all principles that can be employed to assist the process of feeding.

Conclusion

Failure to grow is well documented in infants with complex congenital cardiac disease. This phenomenon is particularly challenging in infants with functionally univentricular physiology. There are a multitude of reasons for the lack of growth in this population, including immature cerebral function, the surgical approach, as well as swallowing and gastrointestinal dysfunction. Strategies to combat this persistent problem of suboptimal gain in weight must be multifactorial, and should include modalities to address not only the medical and physical needs of the infant, but also to include behavioural and environmental components in the form of care bundles. Attention must be given to the cues provided by the infant indicating their readiness for feeding, along with acknowledgement of the responsibilities of the caregiver. There is great need for a systematized approach to feeding that incorporates physiological, neurological, and behavioral assessments, and which can be tracked to assist the infant to achieve success with feeding and optimize the desired gain in weight. As we continue to improve the surgical approach and postoperative care, greater attention must be given to the nutritional needs in this population.

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