Arch Argent Pediatr. 2026;e202510805

Feeding disorders in children with congenital heart disease: clinical implications and the role of the speech and language pathologist

Natalia L. Pugliese[1], *Patricia I. Tabacco*[1], *María del C. Campos*[2]

ABSTRACT

Medical and technological advances have increased the survival rate of children with congenital heart disease, which has led to a deeper understanding of various aspects of their subsequent development. Cardiovascular involvement has a direct impact on feeding, causing sucking and swallowing dysfunctions from birth that can trigger a series of consequences such as malnutrition, dysphagia, and clinical discomfort. This problem not only affects the physiological sphere but also the emotional and family dimensions.

This article summarizes key findings in the growing literature on the impact of heart disease on pediatric nutrition and emphasizes the role of speech-language pathology.

Further research on this issue is needed to provide greater knowledge that improves the quality of life of these children and their families.

Keywords: *congenital heart disease; swallowing disorders; speech and language pathology; caregivers.*

doi: http://dx.doi.org/10.5546/aap.2025-10805.eng

To cite: Pugliese NL, Tabacco PI, Campos MC. Feeding disorders in children with congenital heart disease: clinical implications and the role of the speech and language pathologist. *Arch Argent Pediatr.* 2026;e202510805. Online ahead of print 22-JAN-2026.

[1] *Speech-language Pathology;* [2] *Speech-language Pathology Research Laboratory; Universidad del Museo Social Argentino, Autonomous City of Buenos Aires, Argentina.*

Correspondence to *Natalia Pugliese: fonopugliese@gmail.com*

Funding*: None.*

Conflict of interest: *None.*

Received*: 7-5-2025*
Accepted*: 10-2-2025*

INTRODUCTION

In recent decades, there has been an increase in consultations from families concerned about their children's eating difficulties and weight gain.[1,2] It is estimated that eating disorders affect between 25% and 45% of typically developing children, and between 30% and 80% of those with developmental disorders.[3] Some of the causes of this increase in incidence may be related to reduced mortality, often accompanied by higher morbidity.[1]

Pediatric feeding disorder (PFD), classified in ICD-10 under codes R63.31 (acute) and R63.32 (chronic), is defined as poor oral intake that is inappropriate for age and associated with medical conditions or nutritional, feeding, or psychosocial disturbances.[4] The disorder encompasses mismatches between chronological age and developmental age in terms of adequate oral intake skills, as well as the inability to consume sufficient food and fluids to meet nutritional and hydration requirements.[4]

In this article, the terms "feeding disorders" and "feeding difficulties" will be used interchangeably with the term "pediatric feeding disorder" (as defined in ICD-10).

Some children with complex health conditions at birth develop eating disorders that can persist for an extended period. Children with congenital heart disease (CHD) have a high prevalence of feeding difficulties.[5-8] In addition, this population exhibits reduced growth parameters relative to healthy peers during the first three years of life.[9]

CHDs are the most common heart malformations that occur during prenatal development.[10] They are caused by abnormal embryogenesis of the heart due to multifactorial causes that are not yet fully understood. Genetic and environmental risk factors that may contribute to them have been described.[11]

In Argentina, 1 in every 100 newborns (approximately 7000 per year) has some form of CHD.[10,12] According to the latest registry published by the National Network of Congenital Anomalies (RENAC, by its Spanish acronym), which only records severe CHD, 344 cases were reported in 2023, with a prevalence of 16.29/10 000 live births (95% CI: 14.62-18.11). Less than 10% of cases presented a syndromic condition.[13] During the first year of life, almost 50% of these infants require surgical correction.[12]

Although CHDs are the leading cause of perinatal death and account for 10% of all infant deaths,[14] in recent decades, medical and technological advances have enabled 80% to 90% of children with complex heart defects to survive.[7,15,16] Increased survival has enabled identification of aspects of later development and recognition of potential sequelae associated with severe health conditions that require chronic medication, invasive procedures, and prolonged hospitalizations.[6,16]

Speech-language pathologists play a fundamental role in the detection, assessment, and intervention of eating and swallowing disorders in pediatrics. Their specific training in oromotor, respiratory, and swallowing functions allows them to comprehensively address both primary disorders (derived from the underlying pathology) and secondary disorders (post-surgical sequelae or those associated with invasive devices). Early intervention facilitates the identification of warning signs, the prevention of complications such as aspiration, malnutrition, or growth retardation, and the guidance of caregivers in safe feeding practices adapted to each clinical case. Likewise, the inclusion of speech-language pathologists in transdisciplinary teams contributes to optimizing the safety and efficiency of oral intake, thereby improving the quality of life for the child and their family.[4,6,17,18]

This article aims to provide a narrative review of the current evidence on feeding disorders in children with CHD, describe their pathophysiology, and outline the role of speech-language pathologists in healthcare teams.

Clinical manifestations

Several studies comparing infants with CHD to healthy peers have reported a higher prevalence of PFD among the former. Oropharyngeal dysphagia and difficulty gaining weight were frequently observed. In cases requiring nasogastric tube (NGT) feeding, the transition to oral feeding was prolonged compared with other pathologies. As a result, between 29% and 45% of patients are discharged while still on NGT.

Similarly, between 18% and 74% of infants with congenital heart disease without comorbidities continue to experience some degree of dysphagia after corrective surgery. [7,8,19-21]

A statistically significant correlation was identified between prolonged orotracheal intubation (greater than 24 hours) and the onset of dysphagia. In addition, the median number of swallowing disorders varied according to the feeding method: during breastfeeding, it was one disorder, while with bottle feeding, it rose

to 4 (p = 0.043), which shows a higher risk of incoordination and signs of dysphagia with the latter feeding method. Post-surgical infants had more episodes of sucking-swallowing-breathing incoordination (36.8%) and coughing or choking (42.1%) during bottle feeding, probably due to the higher flow rate.[22,23]

The frequent signs and symptoms of PFD in infants and young children with CHD can be summarized as follows:[5-8,24,25]

- Physiological distress during feeding (tachycardia, fatigue, tachypnea, lethargy, cyanosis, severe dyspnea, hypotension, coughing, choking, nausea).
- Oral motor dysfunction.
- Delayed development of eating skills.
- Significant signs of stress.
- Problematic feeding behaviors (disorganization, disengagement, and refusal to eat).
- Selectivity and restrictive eating.
- Oral sensory processing dysfunction or oral aversion.
- Prolonged transition to full oral feeding.
- Oropharyngeal dysphagia with incoordination of sucking-swallowing-breathing patterns.
- Delay in starting oral feeding after surgery (due to delayed sternum closure, prolonged intubation, among others).
- Growth retardation leading to morbidity and mortality.

In certain types of heart disease, such as single ventricle heart disease, NGT nutrition has been shown to result in inadequate long-term weight gain after surgery.[9] Similarly, infants with cyanotic heart disease and those with hypoplastic left heart syndrome have a higher prevalence of feeding and growth problems.[26]

Long-term studies reported that in 11.5% of 78 children studied, feeding disorders persisted for at least three years after open-heart surgery.[27]

Pathophysiology and associated factors

At birth, feeding is an aerobic function that requires significant energy expenditure and involves the coordination of vital sucking, swallowing, and breathing reflexes to achieve adequate nutritional intake.[5,25] These functions of the stomatognathic system require the integrity of the body's other subsystems to develop correctly.[28]

Thus, heart disease can significantly interfere with the oral feeding process. This failure of physiological homeostatic control during suckling often leads to the adoption of an alternative non-oral feeding route until surgical resolution. Even after corrective surgery, difficulties may persist due to deprivation of oral stimuli and/or aversion caused by the use of oral tubes, cannulas, feeding tubes, and fixation tapes on the patient's face.[5-8,29,30] Patients with CHD who undergo multiple cardiac surgeries and those with early feeding disorders are at risk of prolonged PFD throughout early childhood.[31]

Oromotor difficulties (as well as increased metabolic demand, delayed enteral feeding secondary to prostaglandin infusion, risk of mesenteric hypoperfusion, and prolonged intubation, among others) are among the causes that must also be considered within the multifactorial spectrum leading to nutritional problems in children with heart disease.[19,20] However,unlike the other factors mentioned, oromotor difficulties are not rutinely considered.[4]

Certain factors, such as prolonged NGT use, gastroesophageal reflux, and post-surgical sequelae (e.g., left vocal cord and/or diaphragmatic paralysis) during a critical developmental period, can interfere with oral feeding skills.[29]

Diagnosis and therapeutic approach

It is important to conduct a comprehensive assessment of feeding skills from birth to identify both the patient's difficulties and abilities in achieving efficient, safe, and comfortable feeding. The specialized literature recommends that speech-language pathologists be included in PFD care teams when considering oral skills.[18,24,25]

In the presence of the signs and symptoms described above, consultation with a speech-language pathologist specializing in phono-stomatology, responsible for disorders of sucking, swallowing, and other oral functions, is recommended.[32]

The speech-language pathologist's intervention should begin in the neonatal intensive care unit, given that difficulties manifest from the earliest form of feeding: suckling. This may even be the first warning sign in the absence of a prenatal diagnosis. The main warning signs observed during breastfeeding or bottle feeding include coughing, episodes of choking, increased respiratory effort, tachycardia (>160 bpm), moaning, stridor, cyanosis, paleness, fatigue, prolonged feeds (longer than 30-40 minutes), frequent interruptions in sucking cycles, dysphonic crying, and disconnection.[5,28,33]

After reviewing the patient's history, the

speech-language pathologist conducts a functional assessment of oral feeding skills through clinical evaluation of oromotor development. In some cases, this may be supplemented by instrumental studies, such as videofluoroscopic swallowing studies or fiberoptic endoscopy, particularly when silent aspiration is suspected. Clinical protocols include the analysis of various categories:[34]

- Feeding history.
- Level of consciousness during intake.
- Postural stability and gross motor control.
- Oral sensorimotor physical examination: craniofacial anatomy, oral cavity and tongue, oral reflexes, tactile sensitivity, muscle tone, mobility, and range of motion.
- Functions according to development: sucking, swallowing, sipping, and chewing.
- Synergies between functions and physiological stability during feeding.

The results of the assessment are discussed with the transdisciplinary team in terms of safety and efficiency, to define the most appropriate course of action for each patient: initiate or discontinue oral feeding, maintain a mixed feeding regimen (breast or bottle combined with NGT feeding), indicate therapeutic intervention, implement safe compensatory strategies, or plan the transition from tube feeding to sucking.[28] It is recommended to enable safe oral feeding as soon as possible to prevent the sequelae associated with prolonged tube use, such as deprivation of oral stimuli and gastric and pharyngeal discomfort. When oral feeding is not yet feasible, it is advisable to maintain non-nutritive stimulation and provide positive oral experiences.[23]

Table 1 presents the objectives and strategies of speech-language pathology interventions for feeding children with congenital heart disease.[18,21,23]

However, transdisciplinary treatment should address not only the initial difficulties of nutritive sucking in the neonatal period but also include post-surgical follow-up, both in cases requiring therapeutic intervention for persistent dysphagia and in the monitoring and stimulation of oral skills that the child must acquire at a later age.

The approach must focus on the family, given that infants and young children depend on their caregivers to fulfill this vital function. Parents require clear information, guidance, and professional support, as they are active participants in this situation.[25]

Within this framework, the speech therapist trains the caregiver in co-regulated feeding strategies. This model promotes responsiveness by teaching the adult to recognize the signals the child emits when feeding becomes challenging and to respond appropriately. In this way, the bond of trust between the child and the caregiver is strengthened, promoting positive experiences and healthy learning in feeding.[6]

Clinical perspectives

Children with CHD have feeding or swallowing difficulties in 42.9% (95%CI 30.4-54.4) of cases. Within this group, aspiration has a pooled mean prevalence of 32.9% (95% CI 20-43.25). The prevalence is higher in complex cyanotic CHD (49.9%) than in acyanotic CHD (32.5%). In the postoperative period, PFDs have a variable prevalence ranging from 18% to 83%, and between 31.3% and 58.3% of patients require discharge with a feeding tube. In summary, approximately half of children with CHD may have feeding or swallowing difficulties, and one-third may experience aspiration, especially in neonates, in the postoperative period, and in

Table 1. Speech therapy interventions in feeding children with congenital heart disease

Main objectives	Optimize feeding efficiency and safety. Reduce the effort and duration of feedings. Promote oral organization and bolus management.
Therapeutic strategies	Oral sensorimotor stimulation. Non-nutritive sucking: gloved-finger or empty-breast technique. Transition to nutritive sucking: according to clinical criteria of aptitude. Sucking-swallowing-breathing coordination. Modulation of milk flow speed (probe-finger technique). Postural changes. Administration of breaks. Creation of an appropriate rhythm. Fragmentation of feedings with measured volumes.

complex cardiac malformations.[35-37]

Despite the significance of these figures, feeding and swallowing in children with CHD are often not considered a critical component of care and are frequently perceived as less complex than other medical interventions. However, oral feeding skills are essential for proper development and for achieving the required weight for surgery, although they remain controversial in this population.

In general terms, many families report not having received sufficient professional guidance regarding these difficulties and say they have primarily turned to social networks and parent groups of children with the same condition.[25] Feeding infants and children with CHD represents a significant parenting challenge for adults, so professionals must work closely with them to ensure adequate caloric and nutritional intake for appropriate growth and weight gain.[26]

Since feeding is one of the first parenting tasks, it is essential to prepare families for this aspect when a prenatal diagnosis is made. Although evidence indicates that breastfeeding is safe and effective in most newborns with CHD, anticipating potential difficulties can reduce emotional impact and frustration in cases where exclusive breastfeeding is not feasible before corrective surgery. At the same time, breast milk expression should be encouraged to ensure that the newborn receives expressed human milk (via centrifugation or refrigeration), which is associated with a lower risk of necrotizing enterocolitis and better weight-gain outcomes than commercial formulas.[38,39] In the scientific literature, most of the studies have been conducted with small, unrepresentative, or heterogeneous samples (often with comorbidities), which reinforces the need for further in-depth research into this issue.[30]

CONCLUSIONS

Feeding is a complex process influenced by the physiological and pathophysiological states of multiple body subsystems, including the respiratory, cardiovascular, digestive, neurological, sensory, and psychological systems.

In infants and children with CC, this process is a challenge that the healthcare team should not underestimate. From the beginning of life, it requires specialized care and continuous monitoring. In this context, speech-language pathology intervention is essential for early detection of difficulties, prevention of nutritional and respiratory complications, and guidance for caregivers on safe strategies. Its integration into transdisciplinary teams optimizes swallowing safety and improves the quality of life for the child and their family.

Likewise, further research in this field is essential to broaden understanding and promote a comprehensive approach to the problem. Studies are needed to examine the acquisition of oral feeding skills across different developmental stages—in the short, medium, and long term—to generate evidence to inform clinical practice and care planning. ■

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