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Breastfeeding infants with CHD: an evidence summary and recommendations from the Cardiac Newborn Neuroprotective Network, a special interest group of the Cardiac Neurodevelopmental Outcome Collaborative

Kristin M. Elgersma¹, Jessica A. Davis², Shripriya Mohan-ONeill³, Shannon R. Overpeck⁴, Hema Desai⁵, Jennifer Gauntt⁶, Jairrah L. Godsil⁷, Julie K. Gray⁸, Brittney D Harris Dixon⁸, Sarah W. Hodgson⁹, Cat J. Marks¹⁰, Elizabeth R. Mekler¹¹, Nashifa H. Momin¹², Kimberly Morris¹³, Kacee M. Muller¹⁴, Karli A. Negrin¹⁵, Virginia L. Scheiderer¹⁶, Nancy L. Slater¹⁷, Nellie M. Swanson¹, Samantha C. Butler¹⁸, Jennifer K. Peterson¹⁹

¹School of Nursing, University of Minnesota, Minneapolis, MN, USA

²Healthy Start, Inc., Pittsburgh, PA, USA

³School of Nursing, University of Virginia, Charlottesville, VA, USA

⁴Cardiovascular Intensive Care Unit, Children's Hospital Orange County, Orange, CA, USA

⁵Department of Rehabilitation, Children's Hospital Orange County, Orange, CA, USA

⁶Heart Center, Nationwide Children's Hospital, Columbus, OH, USA

⁷Department of Physical and Occupational Therapy, Children's Mercy Hospital, Kansas City, MO, USA

⁸Rehabilitation and Therapy Services, Children's Medical Center of Dallas, Dallas, TX, USA

⁹Division of Occupational Therapy, Shenandoah University, Winchester, VA, USA

¹⁰Nutrition and Food Services, University of California San Francisco, San Francisco, CA, USA

¹¹Department of Communicative Sciences and Disorders, CS Mott Children's Hospital, Ann Arbor, MI, USA

¹²Department of Rehab, Children's Healthcare of Atlanta, Atlanta, GA, USA

¹³Department of Speech–Language Pathology, Rady Children's Hospital, San Diego, CA, USA

¹⁴Acute Care Therapy Services, Primary Children's Hospital, Salt Lake City, UT, USA

¹⁵Department of Therapy Services, Nemours Children's Health, Wilmington, DE, USA

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Corresponding author: Kristin M Elgersma; elger005@umn.edu.

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¹⁶Pediatric Heart Center: Nursing, University of California San Francisco, San Francisco, CA, USA

¹⁷Physical Medicine and Rehabilitation Services, Children's Minnesota, Minneapolis, MN, USA

¹⁸Department of Psychiatry & Behavioral Sciences, Boston Children's Hospital and Harvard Medical School, Boston, MA, USA

¹⁹School of Nursing, Johns Hopkins University, Baltimore, MD, USA

Abstract

Human milk and direct breastfeeding provide the optimal, biologically normative nutrition for hospitalised infants, with well-established benefits for immune, gut, cardiac, brain, and maternal health. Despite these benefits, human milk and breastfeeding rates for infants with CHD in high-resource countries are typically low, and there are no formal guidelines to drive CHD breastfeeding practice. Our aim is to (1) summarise the evidence on breastfeeding for infants with CHD, (2) discuss key barriers to and facilitators of breastfeeding in this population, (3) identify critical research and practice gaps to improve breastfeeding care in CHD, and (4) provide recommendations for clinical practice and future research.

Primary breastfeeding barriers for infants with CHD include (1) concern for dysphagia/aspiration, (2) concerns related to weight gain, (3) clinical instability/sickness, (4) developmental considerations, (5) general breastfeeding challenges, and (6) workflow and implementation issues, with racism and health disparities also contributing. The evidence to support these barriers is limited and often conflicting. Breastfeeding facilitators for preterm infants are well described, but facilitators may require modification for infants with CHD. Most lactation interventions have not been tested in CHD populations. Current evidence does not support automatic withholding of breastfeeding from infants with CHD; rather, the benefits of breastfeeding likely outweigh many potential concerns. There is a critical need for research and quality improvement to identify interventions that equitably and effectively support breastfeeding for infants with CHD and to evaluate the effect of breastfeeding on short- and long-term physical, psychological, and developmental outcomes for infants and families.

Keywords

heart defects; congenital; milk; human; breast feeding; nutrition

Introduction

Breastfeeding provides the optimal, biologically normative nutrition for all infants. The World Health Organization (WHO) and the American Academy of Pediatrics recommend breastfeeding within the first hour after birth, exclusive breastfeeding (defined as breast milk with no other foods or liquids, except for rehydration solution, vitamins, minerals, or medicines) until age 6 months and continued breastfeeding until age 2 years or beyond.^{1,2} For hospitalised infants, WHO similarly recommends human milk as the nutrition of choice, with transition to exclusive breastfeeding by 6 months whenever possible.³ Breastfeeding and human milk feeding are often conflated in research; however, for this paper, we define

breastfeeding as direct feeding from the lactating parent's breast or chest. Human milk feeding includes maternal and/or donor milk, given by any route. Lactation refers to both breastfeeding and human milk feeding, and we acknowledge that some individuals prefer alternative terminology (e.g., chestfeeding).

While breastfeeding and human milk rates for infants with CHD vary globally, reported prevalence in high-resource countries is typically far lower than in the general population. A US national registry analysis found that, while 63.4% of infants with single ventricle CHD were receiving at least some human milk at hospital discharge (~1 month old; 9.3% exclusive human milk), only 14.4% were directly breastfeeding.⁴ Another US study reported 35% human milk feeding at neonatal discharge,⁵ and infants with CHD in a Norwegian population-based cohort were 1.69 times more likely than healthy infants to discontinue breastfeeding by 6 months.⁶ In these studies, postnatal human milk feeding was initiated at rates similar to the general population (e.g., 85.7% in the US⁷), suggesting that the large majority of parents of infants with CHD intend to breastfeed.

There is limited evidence to guide clinical breastfeeding practice for infants with CHD.⁸ Parents consistently report feeding as a top source of stress,⁹ and qualitative studies describe frequent discordance between institutional/clinician support and parents' breastfeeding goals.^{9,10} Our aim is to (1) summarise the available evidence related to breastfeeding for infants with CHD, (2) discuss key barriers to and facilitators of breastfeeding in this population, (3) identify critical research and practice gaps to improve breastfeeding care for infants with CHD and their families, and (4) provide recommendations for clinical practice and future research, based on the available evidence.

Benefits of human milk and breastfeeding for infants with CHD

The benefits of human milk and breastfeeding for infants are well established, including lower infection risk, reduced infant mortality, decreased chronic disease and disability, and improved neurodevelopment (see Supplementary Table S1). Historically, nutrition and feeding science for critically ill infants has largely focused on preterm populations and on human milk rather than on breastfeeding. This emphasis on human milk is likely due to initially immature oral feeding coordination in preterm infants and to challenges in quantifying breastfeeding volume in a clinical setting. Recent research, however, has identified unique benefits of direct breastfeeding. In both term^{11,12} and preterm¹³ cohorts, breastfeeding has been associated with a favourable human milk microbiota, which likely promotes a healthier infant gut and oral microbiome.^{13,14} Additionally, bidirectional immunomodulation between the infant and parent during breastfeeding (e.g., through retrograde flow of milk from the infant's oral cavity into the mammary gland) likely contributes to changes in immune components of maternal milk, which are customised in response to infant illness.^{15,16} Saliva from the infant's oral cavity interacts with maternal milk to release antibacterial compounds (e.g., hydrogen peroxide) that further inhibit oral pathogens.¹⁷

Emerging evidence on human milk and breastfeeding for infants with CHD is consistent with preterm studies, reporting substantial reductions in necrotising enterocolitis^{18–22} (NEC;

ie, 63–92% lower odds;¹⁸ 11.8% lower incidence¹⁹), infection,²³ sepsis,²² adverse feeding outcomes²⁴ (i.e., gastrointestinal distress and bloody stools), and length of stay,²⁵ and potential improvement in growth^{19,20,24} and neurodevelopment.²⁶ Feeding at the breast, compared to the bottle, has been shown to support greater cardiorespiratory stability during feeding for infants with CHD.²⁷ Moreover, research demonstrates that breastfeeding predicts a longer duration of human milk feeding duration in term, preterm, and CHD⁴ populations. Thus, breastfeeding has the potential to increase exposure to lifespan human milk benefits for infants with CHD and their lactating parents.

Current National Institutes of Health initiatives approach human milk/breastfeeding as an interactive biological system with parent, infant, and environmental inputs,²⁸ highlighting the complex, relational nature of breastfeeding. For hospitalised infants and their families, for whom physical and emotional separation due to medical interventions can disrupt the natural progression of early relationship development, positive breastfeeding experiences may reduce physiologic and psychological stress.^{29,30} Breastfeeding may also improve maternal mental health^{10,31} during this highly traumatising time, which is increasingly recognised as a critical contributor to neurodevelopment for infants with CHD.^{32,33}

Barriers to breastfeeding for infants with CHD

Despite the benefits of human milk and breastfeeding for infants with CHD, many barriers contribute to low breastfeeding rates (Figure 1). Primary barriers include (1) concern for dysphagia/aspiration, (2) concerns related to weight gain, (3) clinical instability/sickness, (4) developmental considerations, (5) general breastfeeding challenges, and (6) workflow and implementation, with racism, social drivers of health, and health disparities also contributing. Recommendations for clinical practice and research priorities to address these breastfeeding barriers are identified in Table 1.

Concern for dysphagia/aspiration

Infants with CHD are at risk for feeding and swallowing difficulties both pre- and postoperatively, with 18–56% of infants with CHD receiving a dysphagia diagnosis, depending on the cardiac lesion.³⁴ Safe, efficient oral intake involves the integration of a complex system of sensory and motor neural pathways. Infants with CHD, however, may have poor state regulation,³⁵ abnormal muscle tone, and difficulty coordinating breathing and swallowing due to neurodevelopmental delay and increased work of breathing.³⁶ These challenges may contribute to limited and overlooked breastfeeding opportunities.

Infants with CHD may also require noninvasive ventilation (e.g., nasal continuous positive airway pressure; high-flow nasal cannula) pre- and/or postoperatively. The risk of aspiration attributable to oral feeding during noninvasive ventilation is unclear. Evidence in preterm populations is inconsistent,^{37,38} while studies of term infants with bronchiolitis have described few adverse events and no aspiration pneumonia related to oral feeding on noninvasive ventilation.^{39,40} Currently, there are no evidence-based oral feeding guidelines for infants on noninvasive ventilation; thus, clinical practices are driven by institutional guidelines, practice traditions, and clinician experience. Further research is needed to

clarify the relationship between oral feeding (including breastfeeding) and aspiration during noninvasive ventilation of infants with CHD.

Interventions to treat CHD (e.g., surgery in proximity to the recurrent laryngeal nerve,⁴¹ prolonged intubation, extracorporeal membrane oxygenation) may increase the risk of vocal fold motion impairment, with subsequent increased risk of dysphagia and aspiration.⁴² The prevalence of aspiration-related complications in CHD is unknown,⁴² however, and there is little evidence about breastfeeding safety in the context of dysphagia or aspiration. One study including infants <6 months old reported significantly greater oral control, less nasopharyngeal backflow, and less laryngeal penetration during breastfeeding compared to bottle feeding in the same infants, using videofluoroscopic swallowing study (VFSS).⁴³ Similarly, Hersh et al.⁴⁴ found that 90% of infants aged 1–6 months with VFSS-diagnosed dysphagia ($n = 80$) had no pulmonary complications with continued breastfeeding and/or bottle-feeding human milk. In contrast, Duncan et al.⁴⁵ reported higher bronchoalveolar lavage markers of pulmonary inflammation in infants diagnosed with aspiration before age 12 months who were counselled to continue breastfeeding ($n = 12$), compared to those who were told to stop ($n = 7$). However, this study has a high risk for bias due to 75% loss to follow-up, no measurement of actual breastfeeding occurrence up to 1 year before follow-up lavage, and low statistical power. Given the inconsistent evidence, there are no accepted practice guidelines for breastfeeding infants with CHD who have dysphagia or aspiration, but the limited evidence suggests that dysphagia/aspiration are not automatic contraindications to breastfeeding.

For infants with CHD and confirmed dysphagia, we recommend early involvement of a feeding/swallowing specialist and an international board-certified lactation consultant (IBCLC) to evaluate several factors: (1) maternal milk supply and flow rate, (2) the infant's capacity to latch effectively and coordinate with the milk flow, (3) the presence of specific etiological factors such as vocal fold motion impairment, (4) dysphagia severity, (5) the infant's medical complexity, and (6) parent feeding goals. As demonstrated by Kenny et al.'s⁴⁶ implementation of a clinical pathway, collaborative and multidisciplinary assessment of these factors can inform appropriate use of targeted strategies to facilitate safe and efficient breastfeeding. Strategies to allow an infant to breastfeed while decreasing dysphagia/aspiration risk include adjustments to positioning, flow rate, and breastfeeding duration/frequency. In the absence of consensus-based pathways, we recommend close monitoring for signs and symptoms of aspiration, instrumental diagnostic assessment as indicated, and multidisciplinary creation of family-centred feeding plans individualised for an infant's physiological stability and dysphagia risk.

Concerns related to weight gain

Infants with CHD may struggle to achieve age-appropriate growth, experience periods of energy deficit, and have higher rates of malnutrition than the general population. A 2022 meta-analysis found that 16.2% of North American children with CHD were underweight and 14.8% had wasting (i.e., weight-for-length z -score < -2), with higher rates preoperatively and a decrease to near-population-level malnutrition rates by 12 months postoperatively.⁴⁷

The perioperative time may be a period of particularly poor growth for infants with CHD due to feeding interruption,³⁴ systemic inflammation,⁴⁸ and perioperative catabolism.⁴⁹ Moza et al.⁵⁰ found that 98.6% of US infants with single ventricle physiology experienced a decrease in weight for age z-score (WAZ) between stage 1 palliation and discharge. The authors concluded that most factors associated with this WAZ decrease were unavoidable as part of the infant's clinical course or as a measure of disease severity. NEC was one potentially modifiable factor associated with poor growth, suggesting that feeding plans targeting NEC prevention (e.g., human milk) could improve growth for infants with CHD.⁵⁰

Common misconceptions among clinicians include that breastfeeding is more “work,” requires more energy and does not support adequate weight gain. The available evidence does not support these concerns, although data are somewhat limited. Studies of critically ill infants have demonstrated significantly lower cardiorespiratory stress with breastfeeding compared to bottle feeding;^{27,51} no difference in energy expenditure between breastfeeding and bottle feeding for preterm infants—despite longer breastfeeding session duration;⁵² and lower energy expenditure in gavage-fed preterm infants fed human milk compared to formula feeding in the same infants.⁵³ Emerging evidence demonstrates similar or improved growth for infants with CHD fed human milk compared to formula^{24,54,55} and no difference in 1-month and 12-month weight trajectories related to breastfeeding,^{24,54,55} suggesting that concern about weight gain should not automatically preclude breastfeeding.

While high-energy fortification is common for infants with CHD, the literature on the topic is inconsistent. Moza et al.⁵⁰ reported that higher caloric density was not associated with better growth by stage 1 palliation discharge, a finding echoed by Cui et al.⁵⁶ and McCrary et al.⁵⁷ Conversely, other studies have reported increases in weight status related to energy-enriched formulas or fortifiers,^{19,58–62} although many of these studies exhibit risk for bias due to small and/or heterogeneous samples,^{59,60,62,63} comparison of weight rather than WAZ, or substantial attrition (e.g., 68% in one study).⁶⁰ Most studies reported more feeding intolerance in the high-energy intervention groups, with varying severity and significance.^{56,60–63} Many studies did not include infants who were breastfeeding or fed human milk, and only two studies were conducted in North America,^{19,62} limiting generalisability. Consequently, optimal fortification strategies in the context of breastfeeding are unknown.

Furthermore, while studies have reported associations between low weight status and postoperative morbidity/mortality for infants with CHD, nearly all studies are retrospective, limiting causal inference. Studies display high variability in patient age range (e.g., neonates;⁶⁴ 30 days–18 years⁶⁵), weight conceptualisation (e.g., continuous WAZ,⁶⁶ WAZ > or ≤ −2,⁶⁵ WAZ decrease >0.67⁶⁷), and measurement timing (e.g., birth,⁶⁸ admission,⁶⁵ preop,⁶⁶ postop⁶⁷), limiting comparability among studies. Ross et al.'s⁶⁶ large, single-site study of children ages 0–5 found that the relationship between WAZ and postoperative mortality was not linear, with increased mortality risk only in cases of WAZ ≤ −2. In contrast, a large national registry analysis demonstrated an association between even mildly low WAZ at birth (−0.5 to −1) and increased risk of postoperative mortality.⁶⁸ Interestingly, excess weight was associated with mortality and adverse outcomes in another analysis of the same registry,⁶⁹ suggesting that not all weight gain is beneficial for children with CHD.

To date, a causal link between population-level higher weight status and improved clinical outcomes has not been established. A 2022 meta-analysis⁷⁰ of the effect of energy- and/or protein-dense enteral feeding interventions on postoperative outcomes demonstrated no significant reduction in ventilator duration or length of stay for infants with CHD. Similarly, reports of large-scale feeding protocol implementation have described improved post-protocol WAZ but no differences in length of stay or mortality.^{71,72} While optimising nutrition, including age-appropriate weight gain, for critically ill infants remains a crucial developmental goal, it is plausible that poor weight status is largely a symptom of critical illness, and the benefit of targeting weight gain as a primary outcome for all infants with CHD is unclear.

Given the limits of the evidence on nutrition, growth, and breastfeeding for infants with CHD, several questions remain. First, it is unclear whether specific groups may benefit more or less from high-energy nutrition intervention; thus, tools for risk stratification are needed. Second, little is known about the optimal timing of high-energy intervention or the relationship between hospital weight gain trajectory and safe discharge/readmission outcomes. Third, there is a need for relevant measures of nutritional adequacy beyond weight gain (e.g., body composition, metabolic biomarkers, developmental indicators), which are currently underexplored in this population. Finally, research and quality improvement efforts are needed to identify methods of incorporating breastfeeding into nutrition plans for infants with CHD, particularly in the context of nutrition fortification. Individualised nutrition plans that consider both clinical needs and caregiver goals should be prioritised. The current evidence does not support automatic withholding of breastfeeding for all infants with CHD due to concern about weight gain.

Clinical instability/sickness

The CHD clinical course varies, and infants may experience periods of physiological instability and sickness. Historical concerns about preoperative feeding safety for newborns with critical CHD have been challenged by studies reporting no increased risk for NEC or other adverse outcomes associated with preoperative feeding.^{73–75} Writing for the Neonatal Cardiac Care Collaborative, Mills et al.'s⁷³ comprehensive review concluded that evidence does not support universal preoperative feeding restriction, including for infants with ductal-dependent circulation or umbilical arterial catheters. Two subsequent publications provide further evidence to support this conclusion. First, a retrospective, multicentre study of preoperatively fed newborns with prostaglandin-dependent lesions reported NEC or adverse events in only 2 of 127 (1.6%) patients, with no lasting clinical implications.⁷⁵ Although 56% of these infants had an umbilical arterial catheter, most (56%) were primarily orally fed, with a median peak daily volume of 29 mL/kg/day. Similarly, Pappas et al.⁷⁴ reported no increase in NEC following a preoperative enteral feeding protocol for infants with single ventricle physiology (65% with umbilical arterial catheter; 56% exclusive oral feeding), despite an increase in preoperative feeding from 39.5 to 75% and a mean volume of 28 mL/kg/day. These data suggest that most infants with critical CHD can safely feed preoperatively, with close clinical monitoring and stable or decreasing haemodynamic support.⁷³ Moreover, these cohorts demonstrate that early oral feeding is often possible for infants with critical forms of CHD.

To date, most preoperative oral feeding evidence does not delineate between breast and bottle feeding, limiting clinical recommendations for preoperative breastfeeding support in the context of critical illness. Two additional clinical considerations impacting breastfeeding initiation and continuation for infants with CHD are volume restriction related to pulmonary overcirculation, low systemic circulation, or general haemodynamic instability; and safe out-of-bed mobilisation.

Volume restriction

While there are no accepted standards for preoperative volume intake for infants with CHD, preoperative feeding protocols often limit feeding volume in infants with diagnoses considered high risk for NEC (e.g., 40 mL/kg/day,⁷⁴ 40–60 mL/kg/day,⁷⁶ 20–30 mL/kg/day).⁷⁷ Research indicates that term infants, feeding ad lib, ingest approximately 15 mLs of colostrum in the first 24 hours,⁷⁸ while infants born ≥ 35 weeks have a mean milk transfer at breast of less than 10 mL/kg on day 1, approximately 20 mL/kg on day 2, and 40–60 mL/kg on day 3 (all lower with caesarean birth).⁷⁹ Considering potentially lower maternal milk production in a stressful ICU environment,⁸⁰ even higher-risk infants with CHD are not likely to exceed volume limits via breastfeeding during the first several postnatal days. To assess milk intake, pre- and post-breastfeeding weights (i.e., “test weights”) may be used to validate volume transfer.⁸¹ Test weights are accurate within 5 mLs of actual volume⁸² and are considered the gold standard for measuring breastfeeding volume.

Safe mobilisation

Clinicians may hesitate to mobilise critically ill neonates due to concerns about equipment dislodgement and haemodynamic instability. A 2018 survey of PICU providers revealed that fear of endotracheal tube or central line dislodgement was the greatest barrier to early mobility.⁸³ However, robust literature on early mobilisation of critically ill children, including a 2018 systematic review,⁸⁴ reveals that early mobility interventions, when tailored to the child’s condition and led by a multidisciplinary team, can be implemented without adverse events.⁸⁵ One study reported a 0.3% rate of medical equipment dislodgement in >4000 early mobilisation events across 82 PICUs in 65 hospitals.⁸⁶ Similarly, Lisanti et al.⁸⁷ demonstrated that children with transthoracic intracardiac lines could be safely held and mobilised following cardiac surgery.

Breastfeeding and milk supply establishment are facilitated by early and frequent skin-to-skin holding,⁸⁸ and a large body of evidence confirms the safety of skin-to-skin care for critically ill newborns in the NICU. Recent studies have demonstrated similar safety and feasibility of skin-to-skin care for newborns with CHD, including intubated infants, with associated benefits for both infant and parent (e.g., stress reduction, haemodynamic stability).^{89,90} To date, the relationship between skin-to-skin care and breastfeeding for infants with CHD has not been examined; however, multidisciplinary staff involvement to support early mobilisation/skin-to-skin holding is a prerequisite to breastfeeding initiation.

Developmental considerations

Primitive infant feeding reflexes facilitate the development of neuromotor pathways for successful feeding (suck-swallow-breathe) coordination.^{91,92} There is a sensitive 8–12 week “window of opportunity” to establish neuromotor pathways for feeding in neonates prior to infant feeding reflex integration.⁹³ For infants with CHD, life-saving medical and surgical interventions may interfere with this crucial timeline (Figure 2).³⁴ Newborns with CHD may also exhibit neurobehavioural differences, including lower attention and state dysregulation, which are associated with poorer oral feeding outcomes.³⁵

In light of these challenges, responsive, infant-driven, early oral feeding support is a critical component of individualised developmental care for infants with CHD.⁹⁴ The developmentally supportive care model promotes individualised interventions that modify both caregiving practices and the environment, based on an infant’s behaviour and responses to stimuli, to optimise neurodevelopmental outcomes.^{94,95} Delayed oral feeding initiation has been associated with poor subsequent development of oral feeding skills for infants with CHD.^{96,97} Breastfeeding is the biologically-normative, developmentally-appropriate first method of newborn oral feeding, and evidence supports a theory of “feeding imprinting,” in which an infant’s earliest oral feeding experience is foundational.^{98,99} Studies in preterm and CHD populations align with this feeding imprinting theory, with breastfeeding as the first oral feeding method predicting not only breastfeeding at hospital discharge and beyond, but also human milk dose and duration throughout infancy.^{99–101} Considering that many infants with CHD experience nasogastric tube feeding both pre- and postoperatively, strategies to facilitate breastfeeding while transitioning from tube feeding are key. However, recommendations for initiation of breastfeeding after tube feeding are sparse and limited to preterm populations.^{102,103} Moreover, parents report that this transition is stressful,¹⁰⁴ suggesting a critical need for cohesive, multidisciplinary clinical guidelines to support the transition from tube feeding to breastfeeding for infants with CHD.

Infants with CHD are never “too sick” or “too unstable” for individualised developmental care, including pre-feeding interventions to support oral feeding and breastfeeding that are appropriate for the infant’s physiologic state. The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) and other developmental care frameworks emphasise that even the most critically ill infants benefit from individualised, neuroprotective, and family-integrated care strategies, which support physiologic stability and neurodevelopment.^{105,106} Interventions and strategies should evolve dynamically as the infant’s status changes throughout hospitalisation. Strategies to facilitate breastfeeding, including pre-feeding interventions, can be found in Table 2. Given the relatively fixed care requirements in the immediate postoperative time and considering the short window of opportunity before feeding reflex integration, we recommend initiating developmentally supportive breastfeeding interventions as early and as frequently as possible during the preoperative time. Two recent quality improvement projects suggest that allowing postnatal time for family bonding and skin-to-skin care is feasible and safe as early as the first hour after birth, with approximately 70%¹⁰⁷ and 91%¹⁰⁸ of infants born with critical CHD successfully receiving this postnatal care.

General breastfeeding challenges

Supportive breastfeeding care requires both clinicians and lactation specialists who have a comprehensive understanding of common breastfeeding challenges and can implement strategies to mitigate breastfeeding issues.¹⁰⁹ Evidence-based lactation education for cardiac clinicians should focus on the importance of establishment and protection of milk supply via manual expression or pumping, assessment of adequate latch and milk transfer, and supportive communication about breastfeeding initiation and continuation.^{109,110} For higher-level support of complicated breastfeeding challenges, IBCLCs and/or breastfeeding medicine specialists are imperative.^{109,110} An IBCLC can offer expertise regarding the use of nipple shields, positioning for infants with ankyloglossia and tethered oral tissue, or pump flange sizing, and can explicitly support the breastfeeding dyad without other clinical requirements.¹⁰⁹ Breastfeeding medicine specialists are board-certified physicians with additional training in lactation and breastfeeding. These specialists provide advanced lactation support, including diagnosis and medical management of lactation-related disorders such as mastitis.¹¹⁰

The literature describes several successful models of unit-based human milk and breastfeeding support for preterm infants, including the Spatz 10-Step and Breastfeeding Resource Nurse model,¹¹¹ the Rush Mother's Milk Club,¹¹² the Encourage, Assess, Transition (EAT) protocol,¹¹³ and Maastrup et al.'s¹¹⁴ nurse training programme focused on breastfeeding-supportive practices. These models incorporate staff lactation education and training, which aligns with parent reports of clinician advocates as key to breastfeeding success for infants with critical CHD.¹⁰ A recent quality improvement project to improve human milk feeding in a paediatric cardiac ICU similarly incorporated broad-scale staff lactation training, along with more intensive "Lactation Superuser" education.¹¹⁵ Taken together, the success of these ICU-based initiatives reinforces the need for specialised breastfeeding care to mitigate breastfeeding challenges in the context of maternal/infant separation, a noxious feeding environment, and competing care priorities in an acute setting.

Workflow and implementation

Implementing clinician education and multidisciplinary breastfeeding support may be challenging in the context of heavy clinical acuity, staff turnover, and specialised medicine. Postnatal physical separation of the infant/lactating parent dyad is common and can be exacerbated by separate birth and children's hospitals. Parents of medically complex infants are often the strongest advocates for their child's feeding plan, yet parents have described some clinicians as ambivalent, dismissive, uncomfortable, and even hostile towards their breastfeeding goals.^{10,116} The currently limited CHD-specific clinician lactation education may contribute to systemic barriers such as unhelpful or inaccurate advice, delayed lactation equipment provision, inadequate developmental care, inconsistent feeding documentation, and ignorance of institutional breastfeeding policy.^{117,118} Lactation education opportunities for parents of infants with CHD are also limited. Given that prenatal lactation education is increasingly recognised as the gold standard, based on evidence of factors that facilitate breastfeeding,¹¹⁹ initiatives to incorporate CHD-focused feeding and lactation consultation into prenatal care (e.g., into fetal cardiology consults or prenatal CHD classes) may be particularly effective. We strongly recommend assessment and documentation of parent

feeding intention and preparation for breastfeeding during the prenatal period. We also recommend that institutions explore video-based education, mobile lactation apps, and peer mentorship programmes to reach more families. Furthermore, there has been little investigation into best practices to support breastfeeding in the context of CHD beyond hospital discharge. Considering that parents of infants with CHD have reported conflicting messaging and inconsistent breastfeeding support throughout the prenatal, hospitalisation, and post-discharge periods,¹⁰ we strongly recommend further research and practice initiatives to develop congruent, collaborative approaches to breastfeeding support across the care continuum.

Contribution of racism, social drivers of health, and health disparities

In the US, parents who identify as Black or Indigenous are significantly less likely to initiate breastfeeding compared to other racial and ethnic groups.¹²⁰ Black and non-Black mothers of preterm infants have comparable lactation goals and initiation rates, but Black infants are half as likely to receive maternal milk at NICU discharge.¹²¹ Similarly, two recent studies found that Black infants with CHD had significantly lower human milk feeding, but not breastfeeding, compared to White infants,^{101,122} although low overall breastfeeding rates may have obscured disparities. Individual and systemic racism can contribute to these disparities.¹²³ For example, research has documented consistent, race-based discrimination by those providing lactation care, with providers consciously and unconsciously offering patients of colour lower quality care and less frequent support.¹²⁴

Systemic xenophobia also contributes to disparities in breastfeeding rates. Migrated lactating parents experience breastfeeding challenges due to language barriers, feelings of isolation, acculturation, mental health challenges, and differing traditional breastfeeding practices.¹²⁵ Institutional barriers for migrant parents and for those who speak a language other than the dominant language include limited cultural sensitivity and institutional trustworthiness, poor access to interpreter services, and practices that disrupt parent autonomy.¹²⁵

Parents belonging to sexual and gender minority groups may face unique breastfeeding challenges. Transgender parents may experience lactation challenges due to gender dysphoria; anatomical, physiological, and hormonal differences that impact human milk production and supply; transphobia; and lack of clinician training in gender-affirming lactation support.^{126,127} Lack of clinician training to support gender-affirming medical care and transphobia exacerbate these challenges.¹²⁸

Contributors to breastfeeding disparities are multifactorial, and systemic racism, xenophobia, and gender bias intersect with other social drivers of health. Measures of socioeconomic status including employment status, income level, insurance type, and educational attainment have been widely associated with lactation outcomes, including for infants with CHD.¹⁰¹ Specifically, lactating parent employment status and medical leave after birth impact breastfeeding.¹²⁹ Lactating parents in the US may experience greater loss of income when breastfeeding ≥ 6 months, which could disincentivize parents from breastfeeding, further exacerbating disparities.¹³⁰ Employment status also intersects with housing stability, food access and security,¹²² and access to health care services that

contribute to an individual's ability to breastfeed.¹³¹ Frequent parent–infant interaction is essential for breastfeeding, yet many families of infants with CHD face logistical challenges that limit bedside presence, such as long-distance travel, financial strain, or lack of hospital accommodations.

Future CHD lactation research should intentionally seek to diversify participant enrolment. White, educated, English-speaking women have been historically over-represented in lactation research, as lactation clinicians, and in clinical teaching materials.¹³² To our knowledge, no interventions to mitigate structural inequities in CHD lactation care have been evaluated. Quality improvement projects focused on CHD lactation support should consider ways to reduce bias and address health disparities. We recommend that institutions prioritise free or subsidised lodging programmes, transportation assistance, flexible parental leave advocacy, and staff training in competent and sensitive care to ensure that all parents feel seen, respected, and supported in their feeding goals. Furthermore, diversification of the workforce and concordance with the patient population can lead to policy changes and practices that dismantle breastfeeding inequalities;¹³¹ however, a recent American Heart Association Scientific Statement outlined critical gaps in workforce diversity in paediatric cardiac care,¹³³ which could contribute to breastfeeding disparities for infants with CHD.

Facilitators of breastfeeding for infants with CHD

Both the WHO³ and the American Academy of Pediatrics¹³⁴ have published clinical recommendations designed to support lactation outcomes for critically ill neonates, although these guidelines are primarily focused on small and preterm infants. Clinical interventions to protect and promote human milk/breastfeeding for preterm infants have been successfully implemented in multiple settings,^{113,135,136} and facilitators of preterm human milk and breastfeeding are well described in recent systematic reviews.^{137–140} While it is likely that preterm lactation interventions apply to hospitalised infants more broadly, these interventions may require modification, and most have not been thoroughly tested in CHD populations. Table 2 outlines evidence-based lactation facilitators for hospitalised infants, describes potential modifications needed for use in CHD populations, and offers considerations for use.

Two CHD-focused quality improvement projects at large US hospitals have successfully implemented known preterm lactation facilitators,^{81,115} including parent education, specialised staff lactation training, breast pumps/supplies, a multidisciplinary focus on skin-to-skin care, donor human milk access, free meals for lactating parents, and pre/post breastfeeding weights. Additional projects involving infants with congenital anomalies, broadly, have implemented oral care with human milk, non-nutritive breastfeeding, and group prenatal lactation education.^{141,142} These projects suggest that, despite the barriers to breastfeeding for infants with CHD, many lactation interventions are safe and feasible. Notably, a 2023 national registry analysis of infants with single ventricle CHD identified preoperative breastfeeding as the strongest clinically modifiable predictor of breastfeeding at hospital discharge,¹⁰¹ suggesting that early initiation of lactation intervention is key.

While the existing quality improvement reports and observational studies are encouraging, there have been no rigorous studies testing interventions to improve breastfeeding in this population. Thus, there are gaps in knowledge regarding (1) which intervention or group of interventions is most effective; (2) ideal timing for each intervention; (3) how interventions might need modification for infants with CHD broadly, within diagnostic groups, and considering individual complexity; and (4) how intervention effectiveness may vary based on family, social, cultural, and institutional factors.

Conclusion

In conclusion, the benefits of breastfeeding for infants with CHD likely outweigh potential concerns, which are not well supported by available evidence. Identifying and sensitively supporting the breastfeeding plans of expectant or new parents of an infant with CHD should be a part of initial assessment and ongoing family-centred, developmentally supportive care. There is a critical need for well-designed research and quality improvement to identify interventions that equitably and effectively support breastfeeding for infants with CHD and to evaluate the effect of breastfeeding on short- and long-term physical, psychological, and developmental outcomes for infants and families. This paper provides a summary of available evidence, and our call to action includes recommendations for clinical practice and a research agenda for the future.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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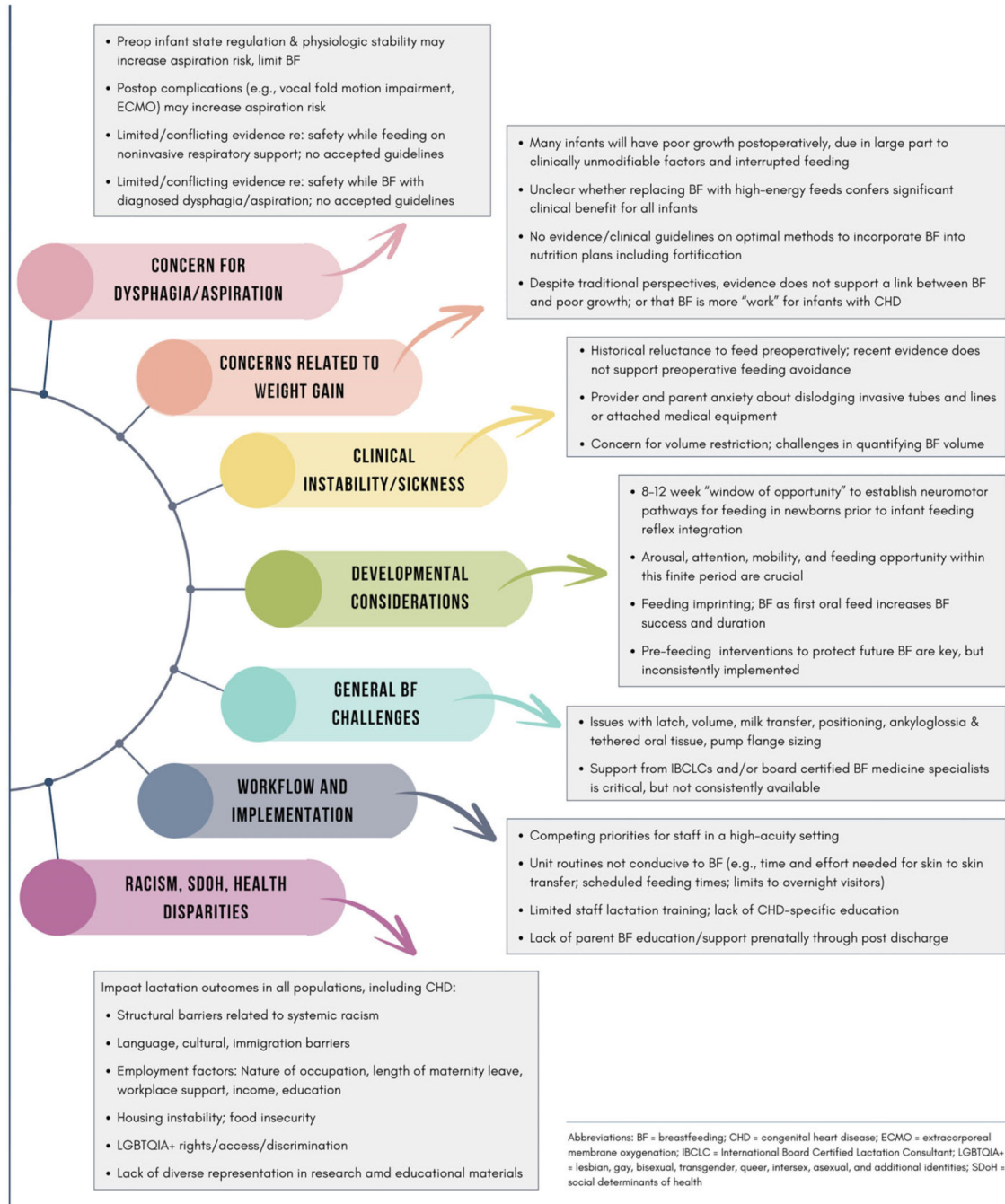


Figure 1.
Primary barriers to breastfeeding for infants with CHD.

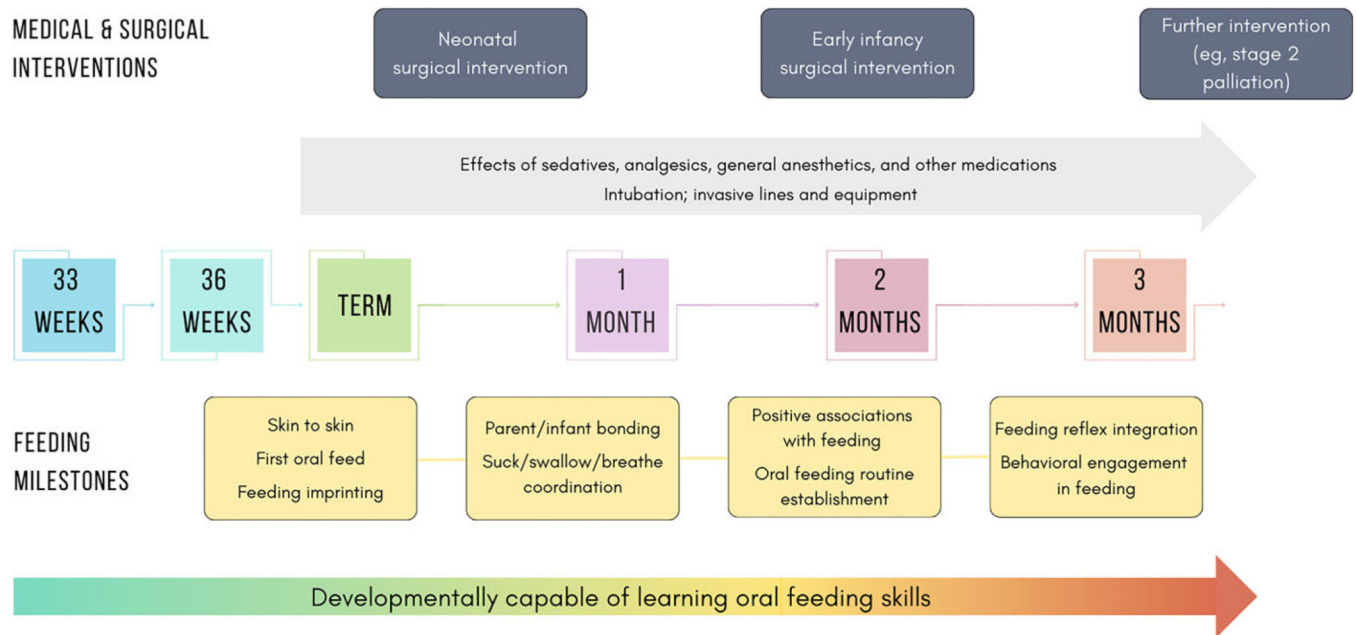


Figure 2.

Medical and surgical interventions for infants with CHD can interfere with the finite developmental window for learning oral feeding skills.

Table 1. Recommendations for clinical practice and research to address barriers to breastfeeding for infants with CHD

Barrier: concern for dysphagia and aspiration
<i>Recommendations for clinical practice</i>
• Prioritise early involvement of a feeding/swallowing specialist and an IBCLC. • Evaluate maternal milk supply/flow, infant latch and coordination, etiological factors (i.e., vocal fold motion impairment), dysphagia severity, the infant's medical complexity, and parent feeding goals. • Incorporate strategies to decrease dysphagia/aspiration risk, including adjustments to positioning, flow rate, and breastfeeding duration/frequency. • Confirmed vocal fold motion impairment: side-lying breastfeeding position with the unaffected side down. • To regulate milk flow rate: Side-lying or laid-back nursing positions; pre-pumping past the initial let down; external pacing to systematically introduce breaks. • Counsel parents to monitor infant stress signs and breathing patterns for indications to discontinue breastfeeding. • Monitor closely for aspiration, with potential for instrumental diagnostic assessment. • Develop and evaluate clinical pathways to safely support breastfeeding for infants with CHD and dysphagia.
<i>Recommendations for research</i>
• Clarify the relationship between dysphagia/aspiration, breastfeeding, and adverse outcomes.
Barrier: concerns related to weight gain
<i>Recommendations for clinical practice</i>
• The current evidence does not support automatically withholding breastfeeding for all infants with CHD due to concern about weight gain. • Increased weight gain may not be an appropriate population-level clinical outcome focus for all infants with CHD.
<i>Recommendations for research</i>
• Identify and test strategies to incorporate breastfeeding into nutrition plans for infants with CHD in the context of nutrition fortification. • Identify groups that may benefit more or less from high-energy nutrition interventions (i.e., risk stratification). • Examine the relationship between hospital weight trajectory and safe discharge/readmission outcomes. • Investigate measures of nutritional adequacy beyond weight gain (e.g., body composition, metabolic biomarkers, developmental indicators). • Investigate relationships among human milk components and infant growth and development in the context of CHD.
Barrier: clinical instability/sickness
<i>Recommendations for clinical practice</i>
• Prioritise early mobilisation and skin-to-skin holding with the lactating parent. • Most infants with critical CHD can safely feed preoperatively, with close clinical monitoring and stable or decreasing haemodynamic support requirements (as recommended by Mills et al.⁷²) • With supportive monitoring, allow stable infants, including those with higher-risk diagnoses, to breastfeed ad lib for the first several days, and potentially longer depending on maternal milk supply. • Develop and evaluate clinical guidelines for preoperative breastfeeding support in the context of critical illness.
<i>Recommendations for research</i>
• Delineate between human milk feeding and direct breastfeeding in nutrition research, particularly in research related to preoperative oral feeding and oral feeding skill development.
Barrier: developmental considerations
<i>Recommendations for clinical practice</i>
• Initiate developmentally supportive feeding interventions as early as possible during the preoperative time. • Prioritise the finite developmental window before feeding reflex integration for modifiable feeding practices (e.g., skin-to-skin care, pre-feeding interventions, early breastfeeding). • Prioritise the “golden hour” immediately after birth for early family bonding, skin-to-skin care, and initial latch attempts, whenever possible. • Prioritise initial oral feeding at the breast for optimal neonatal reflex facilitation and improved breastfeeding and human milk outcomes.

- Develop clinical guidelines to support the transition from nasogastric tube feeding to breastfeeding.
- Practise infant-driven feeding, in which infant cues primarily drive the feeding plan, in contrast to a focus on feeding schedules and volumes.

Recommendations for research

- Investigate the effect of pre-feeding interventions on breastfeeding outcomes for infants with CHD (e.g., skin-to-skin care).
- Investigate effective interventions to improve newborn state regulation in newborns with CHD.
- Investigate the effect of breastfeeding on neurodevelopmental structure and function for infants with CHD.

Barriers: general breastfeeding challenges; workflow and implementation

Recommendations for clinical practice

- Prioritise dedicated lactation support in the cardiac ICU; IBCLCs and/or breastfeeding medicine specialists are imperative.
- Implement broad staff introductory lactation training, with financial support for subsequent specialised staff training. Encourage clinicians to regard lactation support as a standard of care that requires competency.
- Develop clinician and parent lactation education, including focused material on infants with CHD.
- Incorporate CHD-focused feeding and lactation consultation into prenatal care. Assess and document parent feeding intention and preparation for breastfeeding during the prenatal time.
- Adapt, implement, and evaluate existing breastfeeding-supportive protocols (e.g., Spatz 10-step method; EAT protocol) for CHD populations.
- Develop congruent, collaborative approaches that support breastfeeding across the care continuum.

Recommendations for research

- Identify clinical practices that facilitate breastfeeding for infants with CHD.
- Study the implementation of lactation support interventions in paediatric cardiac care.
- Identify which breastfeeding intervention or group of interventions is most effective.
- Investigate the ideal timing for each intervention or group of interventions.
- Investigate best practices for breastfeeding support in the context of CHD across the care continuum.

Contribution of racism, social determinants of health, and health disparities

Recommendations for clinical practice

- Quality improvement projects focused on CHD lactation support should incorporate methods to bias and address health disparities.
- Develop inclusive lactation education materials for both staff and parents.
- Prioritise free lodging, transportation assistance, and flexible parental leave advocacy.
- Train staff to provide competent and sensitive care, ensuring that all parents feel seen, respected, and supported.
- Diversify the clinical staff who are involved in paediatric cardiac care.

Recommendations for research

- Intentionally seek to diversify participant enrolment in CHD lactation research.
- Investigate the effect of social factors (e.g., food insecurity, maternal diet) on human milk composition and infant outcomes in the context of CHD.
- Identify effective interventions to mitigate structural inequities in CHD lactation care.

Table 2.
Breastfeeding facilitators for hospitalised infants, with considerations for use in CHD

Facilitator	Population	Modifications needed in CHD & considerations for use
Parent education		
Prenatal parent lactation education ¹³⁵⁻¹³⁷	Term Infants with congenital anomalies	No current formal parent education specifically geared toward CHD Need considerations for language & cultural barriers (eg in videos, images)
Postnatal parent lactation education ¹³⁰	Preterm (including moderate and late)	Opportunity for inclusion in prenatal appointments; Consider a series of brief check-ins and ongoing conversations, as parents are likely overwhelmed; Consider intersecting with fetal cardiology team Develop consistent institutional BF messaging
Institutional culture and systems		
Specialised staff training: (CLC, IBCLC, BF resource nurse, unit BF champions) ^{107,108,127,131,136}	Preterm (including late preterm/early term)	No formal staff training or education available specifically for CHD populations Provide financial support for staff lactation training Develop a network of BF champions; work toward one available on the unit per shift Ensure accurate BF and human milk documentation; regular audits to track lactation outcomes
Clinical team buy-in, lactation integration, data-driven feedback ¹²⁷		
Family Integrated Care bundle (multiple components; support parents to be primary caregivers) ^{139,140}	Preterm	Similarities to developmental care bundles recommended for CHD populations, ¹⁴¹ effect on BF in CHD is unknown
Positive relationship between parent and healthcare team ^{9,132,142}	Preterm CHD	Establish consistent relationship with a feeding/ lactation specialist pre- and postnatally for continuity of care Integrate lactation assessment into rounds; eg, assess skin-to-skin, pumping support, pre-feeding activities, transition to BF, parent goals
Access to early and frequent milk expression (early postnatal support, hospital-grade pump access, pumping kit) ^{9,138,143}	Preterm CHD Infants with congenital anomalies	Milk expression teaching and resources (pumps, syringes, storage bottles, etc.) planned prenatally if possible; could explore antenatal expression Plan milk transport from birth hospital to children's hospital, as needed Begin milk expression within 1 hour post-birth, if possible, for optimal milk volume
Pre-feeding interventions		
Skin to skin holding (kangaroo care) ^{86,127,133}	Preterm Term	Perform skin-to-skin care as early, often, and long as possible; prioritise throughout stay May need multidisciplinary team (RT, RN); may need parent education Relative contraindications: Infant with open sternum, ECMO, intubated but unstable with care
Non-nutritive BF practice ^{134,144} Positive oral experience at the breast ¹⁴⁵	Preterm CHD Infants with congenital anomalies	Potentially shorter window of opportunity for practice / implementation than for preterm Lactating parent with oversupply needs careful assessment and monitoring Establish the latch as soon as possible preop, as the time near/after surgery is busy with many demands on the baby and heightened concern for volume If concern for aspiration: (1) Practice latch at least 2x/day; (1x with feeding/lactation/RN support) (2) Teach parent to identify milk transfer/swallows and de-latch if consistent transfer
Oral care with colostrum ^{134,146}	Preterm Infants with congenital anomalies	Ideal timing and duration is unclear; only one observational study in CHD
Technologies to support oral feeding and BF (scales for pre/post BF weight, nipple shields, supplemental nursing system, pacifiers for oral stimulation) ^{3,80,107,138,142,147}	Preterm Term CHD	Evidence is mixed with little research in CHD populations; need clear guidelines for use and staff expertise Pre/post BF weights most studied; Once milk transfer/volume are established, regular weights are not needed (can increase parent stress); recommend infant growth as guide Nipple shields should be guided by an IBCLC, only after latching techniques have been attempted

Facilitator	Population	Modifications needed in CHD & considerations for use
Supplemental nursing systems should be guided by an IBCLC; may be used to support pacing via controlled boluses while latching at an empty breast; applicable in cases of dysphagia.		
Breastfeeding skill-building Interventions		
Preoperative BF opportunities ⁹⁹	CHD	If there are volume concerns but the infant is stable, can safely be nutritive ad lib on postnatal days 0–2 based on average milk production volume on these days; potentially longer depending on parent supply
Initial oral feed at the breast / Frequent BF opportunities ^{97,127,148} Protected exclusive BF window for BF establishment/ Avoidance of bottles ^{133,149,150}	Preterm	No evidence in CHD populations; need recommendations for timing, implementation, surgical considerations, etc. There may be different time constraints in CHD populations compared to preterm infants, with a compressed clinical course and critical illness during oral feeding establishment Surgical scheduling may impact institutional ability to provide protected BF window
Abbreviations: BF = breastfeeding; CHD; CLC = Certified Lactation Counselor; ECMO = extracorporeal membrane oxygenation; IBCLC = International Board Certified Lactation Consultant; RN = registered nurse; RT = respiratory therapist.		