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Feeding infants with complex congenital heart disease: a modified Delphi survey to examine potential research and practice gaps

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Abstract

Objective: To determine clinical consensus and non-consensus in regard to evidence-based statements about feeding infants with complex CHD, with a focus on human milk. Areas of non-consensus may indicate discrepancies between research findings and practice, with consequent variation in feeding management. *Materials and Methods:* A modified Delphi survey validated key feeding topics (round 1), and determined consensus on evidence-based statements (rounds 2 and 3). Patients (n=25) were an interdisciplinary group of clinical experts from across the United States of America. Descriptive analysis used SPSS Statistics (Version 26.0). Thematic analysis of qualitative data provided context for quantitative data. *Results:* Round 1 generated 5 key topics (human milk, developing oral feeding skills, clinical feeding practice, growth failure, and parental concern about feeding) and 206 evidence-based statements. The final results included 110 (53.4%) statements of consensus and 96 (46.6%) statements of non-consensus. The 10 statements of greatest consensus strongly supported human milk as the preferred nutrition for infants with complex CHD. Areas of non-consensus included the adequacy of human milk to support growth, need for fortification, safety, and feasibility of direct breastfeeding, issues related to tube feeding, and prevention and treatment of growth failure. *Conclusions:* The results demonstrate clinical consensus about the importance of human milk, but reveal a need for best practices in managing a human milk diet for infants with complex CHD. Areas of non-consensus may lead to clinical practice variation. A sensitive approach to these topics is needed to support family caregivers in navigating feeding concerns.

Over the past four decades, advances in medical and surgical interventions for infants with complex CHD have led to significantly improved outcomes in this population.[1–3] As more infants are expected to survive to adulthood, growth and development has become a primary focus of the healthcare team, with feeding an area of particular concern. Complex CHD increases metabolic and myocardial demand,[4–6] with surgical and neurological complications further putting these infants at risk for feeding-related morbidity and mortality.[7–11] Furthermore, family caregivers report a high level of stress and uncertainty related to infant feeding,[12,13] and feeding problems often become so concerning to families that they overshadow all other cardiac issues.[14] Yet, feeding is a key variable, amenable to treatment, with increased interventions, monitoring, and family support all associated with improved outcomes for these vulnerable infants.[15–19]

In recent years, there have been efforts to address a lack of high-quality evidence[20–22] on best practices for feeding infants with complex CHD. In particular, there is growing interest in the provision of human milk for this vulnerable population, with compelling benefits described in the literature, including reduced risk of necrotising enterocolitis, infection, and sepsis; improved weight gain; and greater cardiorespiratory stability while feeding.[23-29] This emerging evidence, however, is not consistently translated into practice. Instead, there remains centre- and provider-dependent variation in feeding practice.[14,30–34] Many of these variations can lead to suboptimal outcomes for growth and development,[33,35–37] and can result in inconsistent communication between the healthcare team and family caregivers.[20,33,38] Healthcare providers, family caregivers, and affected children would all benefit from increased clarity of understanding in regard to feeding.

The aim of this study was to bring to light areas of consensus and non-consensus in regard to evidence-based statements about feeding infants with complex CHD, with a particular focus on the provision of human milk for this population. For our purposes, infants are defined as ≤ 12 months of age, and complex CHD is defined as CHD that requires surgical intervention within the first year of life. A modified Delphi survey of healthcare experts in complex CHD feeding management is an ideal method to determine the level of clinical agreement on key feeding topics. Areas of non-consensus may indicate discrepancies between research findings and practice, with consequent variation in feeding management. Moreover, by understanding which areas of practice are most vulnerable to uncertainty or disagreement, the healthcare team is better positioned to support family caregivers in flexibly navigating feeding concerns.

Materials and methods

Modified Delphi method

This study used a modified Delphi method. The Delphi method is a multistep survey technique that aims to transform individual opinions into group consensus, based on the assumption that group opinions are more accurate than those of individuals.[39,40] The collective knowledge that unfolds through the Delphi process prompts areas of consensus and non-consensus to emerge. A modified Delphi method is similar to the original Delphi technique in that a group of panelists is surveyed through multiple rounds, with a goal of achieving consensus. However, the modified Delphi technique used in this study began with a comprehensive literature review to develop items for the survey,[41] rather than eliciting open-ended suggestions from clinical experts or stakeholders. This ensured that the survey was evidence-based, and satisfied the objective of determining clinician agreement with the research literature. Figure 1 shows the process used in the study.

Search

To develop an understanding of the current evidence on feeding infants with complex CHD, a search was carried out by KE and ACM, with the assistance of an experienced research librarian.

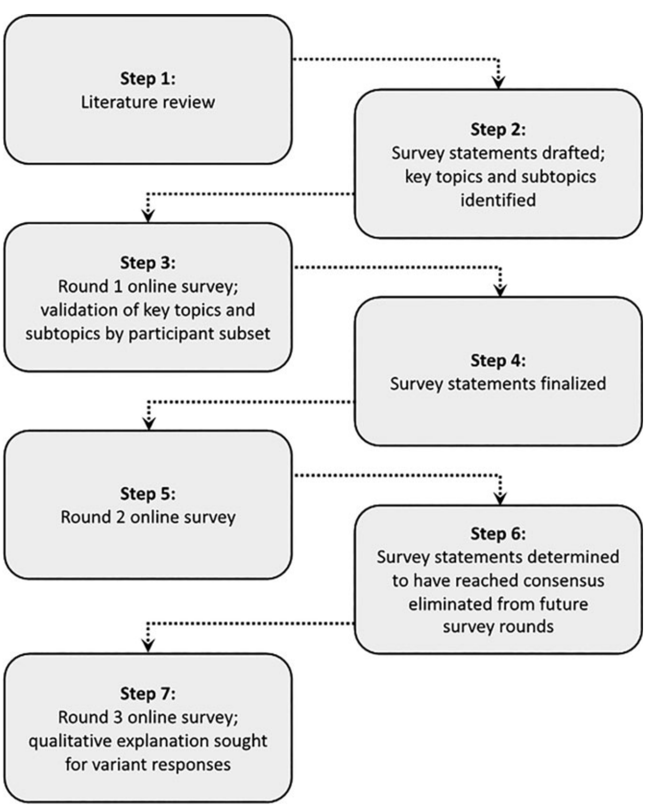

Figure 1. Modified Delphi survey process.

Table 1. Search parameters for literature review

Databases used	Search terms	
Ovid MEDLINE	Congenital heart disease	Hypoplastic
Cumulative Index to Nursing and Allied Health Literature (CINAHL)	Congenital heart defects	Tetralogy
	Congenital heart	Septal
Cochrane Database of Systematic Reviews	Cardiac	Transposition
	Breastfeeding	Infant
	Breast feeding	Baby
Search limits	Breastfed	Babies
Articles published in English	Feeding	Newborn
Articles published from 1990 to 2020	Nutrition	Cardiovascular[a]
	Human milk	Coarctation of the aorta[a]
	Breastmilk	Neonatal[a]
	Breast milk	

[a]Search terms truncated for maximum results

The search strategy can be found in Table 1. After an initial prescreening by title, two authors (KE and ACM) reviewed abstracts following the inclusion and exclusion criteria outlined in Table 2. After the abstract review, it was noted that two authors, Diane Spatz and Barbara Medoff-Cooper, had published widely on the topic of human milk feeding and breastfeeding for infants with complex CHD. To ensure that all relevant evidence was included, the reviewers surveyed all publications generated by these authors, and also examined reference lists for additional studies. A total of 128 abstracts met the inclusion criteria for full-text review, after which 8 articles were excluded, resulting in 120 included articles (Supplementary Table S1). The study selection process can be seen in Fig 2.

Patients

An interdisciplinary group of experts from across the United States of America was sought. These experts fulfilled one of the two possible inclusion criteria: (1) A minimum of 5 years of clinical experience feeding infants with complex CHD in an ICU setting (e.g., neonatal ICU, paediatric ICU, or cardiovascular ICU); or (2) Expertise on nutrition and feeding for vulnerable infants in an ICU setting, including infants with complex CHD, as evidenced by (a) at least three first-author publications on a topic relevant to feeding infants with complex CHD; or (b) a national and/or international profile as an organisational leader, journal editor, or presenter on topics relevant to feeding infants with complex CHD. Experts who agreed to take part were not provided information about any other patients. All data were collected through Qualtrics (Provo, UT, USA) survey software. Patients were provided a $25 Amazon.com gift card upon completion of each survey round, in recognition of their time and effort.

Round 1

The first round focused on the development and validation of content to inform subsequent rounds. A full review of the included literature was conducted, and findings determined to have relevance for both the healthcare team and family caregivers of infants with complex CHD were represented by evidence-based statements (e.g., statements taken directly from the results of the literature review). All statements were generated and organised by subtopic and topic by the first author (KE), and reviewed by the second (ACM) and third (TG) authors. A full list of topics, subtopics, and statements can be seen in Supplementary Table S2.

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Table 2. Inclusion and exclusion criteria for search

Inclusion criteria	Exclusion criteria
Original research article or review	Not published in English
Sample comprised of infants < 12 months old	Published before 1990
Research focused on:	Entire sample not < 12 months old at the beginning of the study
Breastfeeding and CCHD	Sample comprised solely of infants with non-complex CHD (not requiring surgical intervention within the first year).
Feeding substances for infants with CCHD (e.g., human milk, formula, fortifiers)	Research focused on
Hospital interventions to increase breastfeeding, pumping, and/or human milk in the CCHD population, including educational interventions for parents or nurses	preterm infants, with no clear relevance to the CCHD population
Development of feeding algorithms for infants with CCHD	Complications of CCHD with no feeding-specific intervention
Interventions to improve nutritional status for infants with CCHD	Management of CCHD with no or limited feeding-related content
Risk factors for malnutrition/low weight gain in infants with CCHD	Parental stress/needs, with no clear focus on feeding
Feeding interventions for complications in infants with CCHD (e.g., chylothorax, NEC)	Healthy infants
Nutritional challenges for infants with CCHD	Surgical techniques or medical management strategies
Substantial discussion about parents' feelings/stress around feeding infants with CCHD	Ethics, attitudes, beliefs, or education of healthcare providers, with no relevance/application for parents
Breastfeeding or human milk provision for infants with other major anomalies that provided relevant information for the CCHD population	Improving institutional/unit practice with no description of feeding-related outcomes (does not include reviews of institutional feeding practices)
Feeding for vulnerable infants (e.g., premature infants) that provided relevant information for the CCHD population	Risk factors for placement of a feeding device
	Does not otherwise meet inclusion criteria

CCHD = complex congenital heart disease; CHD = congenital heart disease; NEC = necrotising enterocolitis

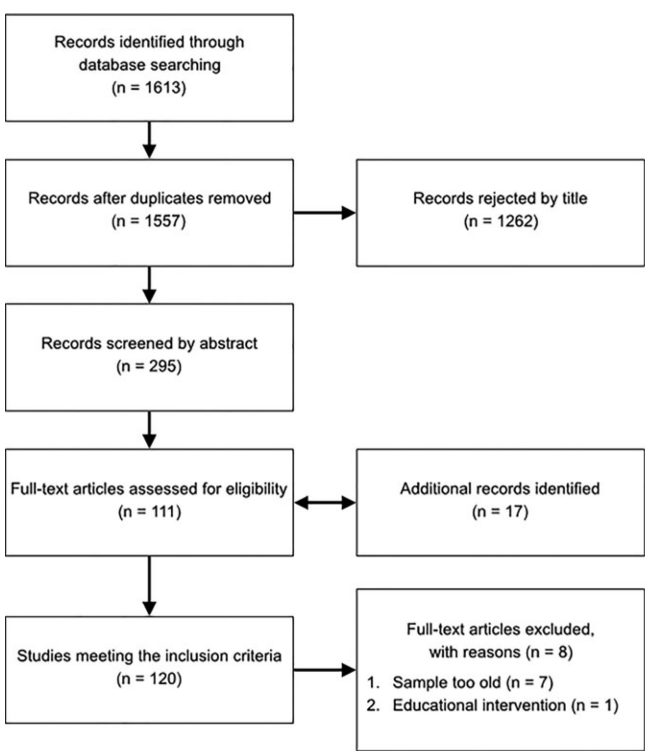

Figure 2. PRISMA flow diagram of the study selection process.

To validate the topics and subtopics, a subgroup of six patients was surveyed. These experts were asked to indicate the extent of agreement or disagreement in regard to the importance of each topic. A 6-point Likert scale was used, with 1=strongly agree [about the importance of the topic or subtopic] and 6=strongly disagree. Additionally, an open-ended response option queried whether any topics or subtopics had been overlooked.

Round 2

The results of round 1 were analysed, and topics or subtopics determined to be of lower importance (a mean greater than or equal to 3) were excluded. The remaining 5 topics, 38 subtopics, and 206 evidence-based statements comprised the round 2 survey. This survey was sent to the full group of 25 clinical experts, who were asked to indicate how strongly they agreed with each statement, using the same 6-point Likert scale. To preserve the anonymity of respondents' answers, surveys were not linked to patients' contact information, and patients were not provided with their responses in subsequent rounds.

Round 3

After analysis of round 2, statements that did not lean strongly towards an agree (mean ≤ 2) or disagree (mean ≥ 4) response or those with a wide range (standard deviation > 1) were included in round 3, which was sent to patients approximately 1 month after round 2. Each statement was presented with its mean, standard deviation, and range, and respondents were asked to answer again using the same 6-point Likert scale, considering the mean group response. If a patient selected a response option that differed in valence from the mean (e.g., choosing a "disagree" answer of 4, 5, or 6 when the mean was 2.4, or "agree"), explanatory comments were elicited. This qualitative response offered insight when there were quantitative outliers.

Data analysis

For each round, Qualtrics data were exported to IBM SPSS Statistics (Macintosh, Version 26.0) to calculate descriptive statistics. Data from round 2 were analysed in a multistep, iterative process to determine the most meaningful approach for including statements in round 3. The mean and standard deviation, median and interquartile range, and percentage of consensus were considered. It was determined that mean (standard deviation) 2.01–4.99

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(> 1) resulted in the highest and most inclusive number of statements of non-consensus.

In round 3, the top 10 statements of greatest consensus were considered to be those closest to a mean of 1 ("strongly agree") or 6 ("strongly disagree"). Statements with the lowest level of consensus were identified in two ways. First, the 10 statements with means closest to the middle (3.5) were considered to show a lack of definitive agreement or disagreement. Second, the ten statements with the highest standard deviation demonstrated the widest range of opinion. Qualitative data from round 3 were analysed through two cycles of coding.[42] The first coding cycle focused on theming the data to identify pertinent information or meaning within a comment. The second cycle involved pattern coding to reduce findings and form higher order themes along with corresponding illustrative quotations.

Results

Patient description

A cohort of 25 experts agreed to participate in this study. The patients were affiliated with 13 academic and clinical sites across the United States of America, and located in the (n,%) Midwest (15, 60), East (5, 20), Southwest (3, 12), and Southeast (2, 8) regions. The experts represented a variety of disciplines, including (n, %) physicians (7, 28), International Board Certified Lactation Consultants (IBCLC; 6, 24), advanced practice nurses (4, 16), skilled feeding therapists (e.g., speech-language pathologist, occupational therapist, physical therapist) (4, 16), dieticians (4, 16), nurse scientists (3, 12), and registered nurses (2, 8). Several experts held multiple certifications (e.g., registered nurse and IBCLC). Fifteen of the 25 had more than 10 years of clinical experience working directly in feeding infants with complex CHD in an ICU setting.

Of the 13 patients' academic and clinical sites, 8 are urban teaching hospitals. One is a > 400-bed adult and paediatric academic medical centre. The remaining 7 are dedicated children's hospitals, with 100–200 beds (n=2), 201–300 beds (n=1), 300–400 beds (n=2), and > 400 beds (n=2). Six of these children's hospitals include a Level IV neonatal ICU.

Round 1

Based on a full review of the evidence, the authors identified five key topics addressed in the literature: (1) human milk, (2) developing oral feeding skills, (3) clinical feeding practice, (4) growth failure, and (5) parental concerns about feeding. In round 1, 6 (100%) surveys were completed, and respondents strongly agreed that all key topics were important for parents and family caregivers of infants with complex CHD. Two subtopics (support of oral feeding using cup feeding; support of oral feeding using finger feeding) did not meet the criteria for inclusion and were removed from consideration.

Based on open-ended responses, 28 additional evidence-based statements were added to subsequent survey rounds. This resulted in a final total of 206 evidence-based statements for inclusion in round 2 of the modified Delphi survey. The complete results of the round 1 survey can be seen in Table 3.

Round 2

In round 2, 25 (100%) surveys were completed, with 89 (43.2%) statements reaching consensus (Supplementary Table S2). The topic of parental concern about feeding contained the highest percentage of statements reaching consensus (78.6%), while the topic of growth failure included the lowest percentage of statements reaching consensus (25%). The 117 statements that did not reach consensus in round 2 moved on to the final round of the modified Delphi survey process.

Round 3

A total of 23 (92%) surveys were completed in round 3. Of the 117 statements, 21 (17.9%) moved to a state of consensus, resulting in a final total of 110 (53.4%) statements of consensus, and 96 (46.6%) statements of non-consensus. The results of the round 3 survey, including all statements reaching consensus, can be seen in Supplementary Table S2. Parental concern about feeding remained the topic with the highest percentage of statements reaching an agreement, followed by human milk, clinical feeding practice, developing oral feeding skills, and growth failure (Fig 3).

The 10 statements with the highest level of consensus all received "strongly agree" responses and are listed in Table 4. The 10 statements with the lowest level of consensus determined by both mean and standard deviation are presented in Table 5. Qualitative findings for 10 themes are shown in Table 6, with illustrative quotations. These quotations provide insight into the variation in current thinking that is guiding practice.

Discussion

In this modified Delphi survey, we identified areas of clinical consensus and non-consensus on evidence-based statements in regard to feeding infants with complex CHD. To our knowledge, this is the first study to examine clinical opinion on the provision of human milk for this population. Topics of non-consensus emerged through analysis of quantitative and qualitative data, and suggested potential gaps between research findings and practice. An improved understanding of these gaps is a critical first step towards future testing and refinement of feeding approaches for infants with complex CHD.[36] We first discuss the most notable area of consensus in this survey, and then turn our attention to five topics of non-consensus that spurred considerable discussion amongst the clinical expert patients. These areas of non-consensus are considered in the context of the available evidence, and suggestions for future directions are provided.

Consensus

The results of this study highlight the critical role of human milk in feeding infants with complex CHD. The 10 statements reaching the highest level of consensus amongst clinical experts (Table 4) strongly support the provision of human milk as the first-line, preferred nutrition for infants with complex CHD,[24,43] and indicate that human milk provision is a necessary medical and nursing intervention for this vulnerable population.[23] Study patients validated the existing body of research demonstrating that human milk is safe and effective for infants with complex CHD,[15,23,44–46] with advantages such as a reduced risk of necrotising enterocolitis,[6,29,47] infection prevention,[24,25,44,46,48] improved post-operative recovery,[44] a reduction in total number of parenteral nutrition days,[49] and strengthening of the caregiver/infant bond.[50] While the literature describes several interventions designed to improve rates of human milk feeding and breastfeeding for the general neonatal ICU population,[51] only one model of care has demonstrated improved outcomes in infants with complex surgical anomalies,

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Table 3. Round one results: validation of key topics and subtopics

Key topics and subtopics[a]	Level of agreement[b]	
	Mean (SD)	Range
Topic 1. Human milk	1.00 (0.00)	1–1
1.1 Benefits of human milk	1.00 (0.00)	1–1
1.2 Feasibility of providing human milk	1.17 (0.37)	1–2
1.3 Nutritional and/or caloric supplementation of human milk	1.17 (0.37)	1–2
1.4 Potential barriers to providing human milk	1.33 (0.47)	1–2
1.5 Pumping or hand expressing human milk	1.17 (0.37)	1–2
1.6 Breastfeeding	1.17 (0.37)	1–2
1.7 Donor human milk	2.00 (1.83)	1–6
1.8 Role of healthcare team in educating parents/caregivers about human milk	2.00 (0.82)	1–3
1.9 Role of parents/caregivers in becoming educated about human milk	2.00 (0.82)	1–3
1.10 Appropriate timing of parent/caregiver education about human milk	2.00 (1.15)	1–4
Topic 2. Developing oral feeding skills	1.00 (0.00)	1–1
2.1 Feasibility of oral feeding	1.00 (0.00)	1–1
2.2 Risk factors for oral feeding problems	1.83 (1.07)	1–4
2.3 Methods to assist in the development of oral feeding skills	1.17 (0.37)	1–2
2.4 Support of oral feeding using cup feeding	*4.00 (2.24)*	*1–6*[c]
2.5 Support of oral feeding using finger feeding	*4.17 (1.77)*	*1–6*[c]
2.6 Support of oral feeding using bottle feeding	1.33 (0.47)	1–2
2.7 Support of oral feeding using breastfeeding	1.17 (0.37)	1–2
2.8 Prevalence of dysphagia	2.33 (0.75)	1–3
2.9 Treatment options for dysphagia	2.17 (0.69)	1–3
Topic 3. Clinical feeding practice	1.33 (0.75)	1–3
3.1 Feeding practices to expect during preoperative time	1.17 (0.37)	1–2
3.2 Feasibility of early enteral feeding	1.67 (1.11)	1–4
3.3 Safety of early enteral feeding	2.00 (1.41)	1–5
3.4 Benefits of early enteral feeding	1.33 (0.47)	1–2
3.5 Information about trophic feeds	2.00 (1.41)	1–5
3.6 Feeding practices to expect during the post-operative time	1.17 (0.37)	1–2
3.7 Timing of post-operative feeding	1.67 (0.75)	1–3
3.8 Evidence-based recommendations for advancement of post-operative feeding	2.00 (1.41)	1–5
3.9 Benefits of post-operative feeding	1.50 (0.76)	1–3
3.10 Issues related to post-operative growth	1.17 (0.37)	1–2
3.11 Interventions to prevent post-operative feeding problems	1.50 (0.76)	1–3
3.12 Information about necrotising enterocolitis	2.33 (1.80)	1–6
3.13 Interdisciplinary healthcare team/family approach to feeding	1.00 (0.00)	1–1
3.14 Feeding practices to expect post-discharge and/or during interstage period	1.00 (0.00)	1–1
3.15 Fortification (e.g., fortification of human milk)	1.17 (0.37)	1–2
3.16 Home monitoring programs which facilitate frequent contact between healthcare team and children who are interstage	1.17 (0.37)	1–2
3.17 Feeding tubes	1.17 (0.37)	1–2
Topic 4. Growth failure	1.33 (0.47)	1–2
4.1 Risk factors related to growth failure	1.50 (0.50)	1–2
4.2 Energy needs	1.50 (0.76)	1–3

(*Continued*)

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Table 3. (*Continued*)

Key topics and subtopics[a]	Level of agreement[b]	
	Mean (SD)	Range
4.3 Prevention and treatment of growth failure in hospital	1.33 (0.47)	1–2
4.4 Prevention and treatment of growth failure post-discharge and interstage	1.33 (0.47)	1–2
Topic 5. Parental concern about feeding	1.00 (0.00)	1–1

[a]All topics and subtopics refer specifically to infants with complex congenital heart disease (CCHD)
[b]The importance of each topic and subtopic for parents and caregivers of infants with CCHD was rated from 1 (strongly agree/very important) to 6 (strongly disagree/not at all important)
[c]Items with a mean > 3.00 were eliminated from future rounds. These items are italicised

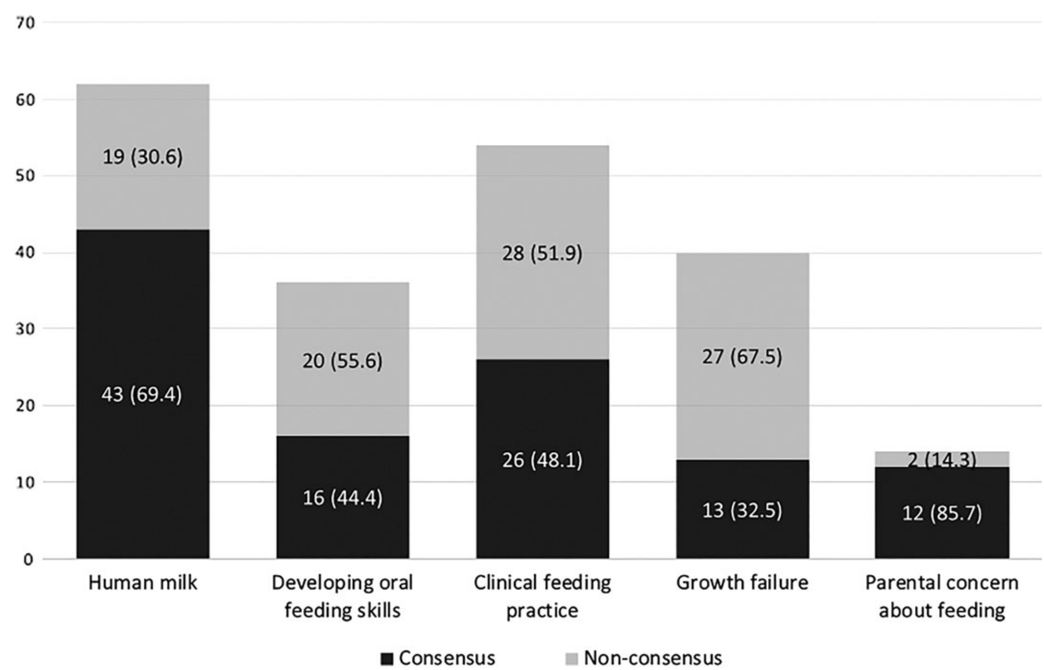

Figure 3. N (%) of statements reaching consensus in each topic.

including those with complex CHD.[15,24] Future work is needed to ameliorate both the reported low rates of infants with complex CHD who receive human milk from birth, and the high risk for early weaning in this population.[52,53]

Non-consensus

Human milk

On the topic of human milk, there were two primary areas of non-consensus. First, the adequacy of human milk to support growth and the need for supplementation or fortification was an area of disagreement, with low consensus as to whether human milk can support the energy needs of infants with complex CHD. The literature is also inconclusive on this issue. Of the seven studies identified that compared human milk to formula and/or supplementation, two demonstrated greater weight loss in the formula/supplementation group,[27,48] and one in the human milk group.[54] The remaining four studies, including the only randomised controlled trial on this topic, found similar weight gain between the two groups.[44,45,55,56] Taken together, the results from the literature indicate that it may be possible for many infants with complex CHD to achieve similar or improved growth on an unfortified, exclusive human milk diet, as compared to formula or other supplementation. To our knowledge, there have been no long-term studies examining the potential for an exclusive human milk diet in infants with complex CHD from birth into the first year of life, and none investigating techniques for targeted management of human milk (e.g., testing calorie content, fractionating milk for higher fat content[57,58]) in this population. In light of the inconclusive nature of the literature, we recommend that clinicians adopt an attitude of creative inquiry when managing growth and development, with a focus on structure and support for family caregivers to provide an exclusive human milk diet for their infant whenever possible. More research is needed to identify and validate best practices in managing exclusive human milk diets in infants with complex CHD.

The second area of non-consensus related to the topic of human milk involved the safety and feasibility of breastfeeding for infants with complex CHD. Patients held a range of opinions on whether breastfeeding is more work than bottle feeding for these infants, but offered a limited explanation for their responses. An often-cited study on this topic demonstrated that breastfeeding causes less cardiorespiratory stress in infants with complex CHD,[26] with similar results reported in other at-risk populations.[59,60] Yet, nearly one-quarter of the clinical experts in this study agreed that breastfeeding is more work for infants with complex CHD. This discrepancy between research findings and clinician perspective suggests that the traditionally held idea that breastfeeding is too difficult for infants with complex CHD[14,38] may still exist today. This is not surprising, given the dearth of research on this topic. In reviewing the

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Table 4. Statements with the highest level of consensus

Statement	Mean (SD)
1. Pumping should be discussed as part of the treatment plan.	1.00 (0.00)
2. Skin-to-skin contact between parents or caregivers and their infant should be a priority of the healthcare team.	1.00 (0.00)
3. Skin-to-skin contact between a mother and their infant facilitates human milk feeding of mother's own milk.	1.04 (0.20)
4. Human milk is the preferred option for initiation of preoperative enteral feeds.	1.04 (0.20)
5. Human milk has advantages for the health of a child with CCHD.	1.08 (0.28)
6. Human milk feeding is an important topic for consideration in all stages of care, including in the ICU.	1.08 (0.28)
7. Human milk should be the first-line nutrition of choice for infants with CCHD.	1.12 (0.33)
8. Human milk education should be a priority before birth.	1.12 (0.33)
9. Ensuring parents have access to coherent and accurate knowledge about human milk supply techniques and benefits facilitates human milk feeding.	1.12 (0.33)
10. The relationship between parents and the healthcare team, in terms of consistent support and education, helps facilitate human milk feeding.	1.12 (0.33)

CCHD = complex congenital heart disease; ICU = intensive care unit

literature since 1990, 12 publications specifically focused on breastfeeding infants with CHD were identified,[23,26,27,38,61–68] including only 6 research studies (excluding case studies). Future research is needed to more fully understand the safety and feasibility of breastfeeding in the context of complex CHD, and best practices to support caregivers in achieving direct breastfeeding with these vulnerable infants should be identified and widely implemented.

Feeding tubes

Statements on tube feeding were subject to non-consensus throughout the study. Best practices in the use of nasogastric tubes to supplement oral intake and the potential impact of nasogastric feeding on the development of oral feeding skills emerged as key areas of discussion. Clinicians did not agree on a strategy for organising and timing nasogastric feeds (e.g., restricted oral feeds; continuous feeds at night), and most of the discussion centred around optimising opportunities for cue-based oral feeding. Few studies identified in the literature focus specifically on nasogastric feeding for infants with complex CHD, and their small sample sizes preclude generalisation.[69,70] Thus, clinicians and centres are left to craft guidelines that may be largely based on tradition and centre-specific experience, with resultant variation in clinical practice.[64] Especially considering that the timing and organisation of nasogastric tube feeding and the progression to oral feeding can be a major source of stress and frustration for family caregivers,[12,14,71] future work to delineate evidence-based, infant-centred, holistic best practices is crucial for improving the standard of care in this area.

Patients did not agree about the ability of supplemental tube feeding to mitigate weight loss or facilitate catch-up growth after discharge. While it seems logical that tube feeding would lead to at least some catch-up growth, particularly in very sick infants

Table 5. Statements with the lowest level of consensus

Lowest consensus, according to mean		Lowest consensus, according to standard deviation	
Statement	Mean (SD)	Statement	Mean (SD)
1. Infants who are directly breastfeeding will need to supplement with bottle or tube feedings.	3.52 (1.04)	1. It is possible for infants with CCHD to gain enough weight from an exclusively human milk diet.	2.83 (1.19)
2. Supplementation by tube feeds does not mitigate growth failure.	3.48 (0.73)	2. Breastfeeding is more work than bottle feeding for infants with CCHD.	4.17 (1.15)
3. Infants with CCHD who are working on developing oral feeding skills should be encouraged ad libitum oral feeding during the day (8–12 hours), then provided the balance of the daily nutritional needs by continuous feeding at night.	3.48 (0.95)	3. Human milk may not have adequate caloric strength to support growth in infants with CCHD.	2.70 (1.15)
4. Most infants will be unable to reach calorie goals of 100–120 kcal/kg/day by hospital discharge.	3.62 (0.74)	4. NG tubes often negatively impact the development of oral feeding skills.	3.13 (1.14)
5. A G-tube is a marker for greater severity of illness.	3.63 (1.12)	5. A G-tube is a marker for greater severity of illness.	3.43 (1.12)
6. A shorter duration of parenteral nutrition therapy is associated with lower weight-for-age z score at hospital discharge.	3.72 (0.75)	6. The decision to begin oral feeding is generally made by the healthcare team through evaluating the infant's physiologic stability, with little attention given to developmental cues for success.	2.77 (1.07)
7. Very slow and cautious escalation of feeding volumes is protective against necrotising enterocolitis.	3.19 (0.87)	7. Most infants will need to supplement to a higher number of calories than human milk can provide.	2.70 (1.06)
8. Exclusively breastfed infants will lose more weight than those who receive supplemental feeds via bottle or feeding tube.	3.82 (0.85)	8. Feeding protocols promote consistent communication between healthcare providers and families.	1.78 (1.04)
9. All patients with single-ventricle physiology will require parenteral nutrition before stage 1 palliation and in the early post-operative period.	3.16 (0.60)	9. For infants who experience dysphagia, bottle feeding leads to more swallowing difficulty than does breastfeeding.	2.91 (1.04)
10. Infants who take at least 50% of their feeds orally prior to surgery will likely be able to reach 100% oral feeding by discharge.	3.15 (0.67)	10. Infants who are directly breastfeeding will need to supplement with bottle or tube feedings.	3.52 (1.04)

CCHD = complex congenital heart disease; G-tube = gastrostomy tube; NG = nasogastric

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Table 6. Thematic areas of non-consensus with illustrative quotations

Theme quotation	Survey topic and statement
1. Ability of human milk to adequately support growth	
"This depends on the age of the infant and whether the infant is preterm. The increased REE and thus caloric demand of many CCHDs combined with the frequent need for fluid restriction in those characterized by CHF would make it difficult to meet demands with unfortified [MOM]."	T1[a], S13[b]
"While I agree that most infants might need increased calories, that doesn't mean we can't use human milk to meet that need (hind milk)."	T1, S14
"It is about knowing the science of human milk and appropriate management"	T1, S14
"Caloric value of human milk can vary significantly."	T1, S15
"There have not been sufficient studies evaluating the effects of exclusive human milk diets in this population, and insufficient data describing human milk composition."	T1, S15
2. Breastfeeding safety and feasibility	
"The longer you go without trying breastfeeding, the harder it is to get the infant to go to breast later . . . all infants should have SOME time at the breast, even if it is minimal."	T1, S37
"I find that there are always ways to incorporate at least some breastfeeding for practice and bonding, rather than viewing it as an all or none activity."	T1, S39
"Some infants struggle with the increased effort required for breast feeding and have an easier time transitioning to bottling."	T1, S32
"There is not research data to support [breastfeeding is more work than bottle feeding]. It is perception that infants take more."	T1, S32
"In the context of the NICU, if an infant is exclusively breastfeeding from the breast with no supplementation, they will tend to lose more weight than formula-fed infants."	T4, S164
"I strongly disagree [that exclusively breastfed infants will lose more weight] because of the infants I have worked with who are exclusively breastfed."	T4, S164
3. Accuracy of pre/post-weights in measuring breastfeeding volume	
"Significant variance and user error can preclude accurate results with this method."	T1, S33
"With correct technique! It is the gold standard in research."	T1, S33
"I find this to be pretty inconsistent and for some families a source of stress as they then focus on the volumes rather than the experience of breastfeeding. Many will choose bottle over breast due to their ability to see the volumes the infant is taking. Whether we like it or not, our NICU/PICU environment still seems to be very volume-driven."	T1, S33
4. Impact of human milk feeding of MOM on caregiver stress	
"This may be dependent upon whether the mother is making a plentiful milk supply, the family's perceptions of the importance of human milk, and [whether] expressing milk is not perceived as difficult or stressful.	T1, S9
"Research shows that performing human milk oral care is important for attachment and bonding and mothers report it motivates them to pump. This would be stress relieving. Also the hormones of lactation are stress relieving."	T1, S9
"If not able to breastfeed, sometimes the burden of having to pump, then feed child by bottle can increase the family's stress due to time consumption."	T1, S9
"I strongly disagree [that human milk feeding of MOM increases stress] UNLESS the institutional culture does not support the parents."	T1, S10
"This is completely situation dependent."	T1, S10
5. Infant feeding cues	
"Parents of infants with CCHD are often very concerned about intake and this leads to misinterpretation or second-guessing [of feeding cues]."	T5, S196
"Due to infant's sleepy nature [feeding cues] are less obvious."	T5, S196
"I think parents can do a remarkable job of reading and responding to their infant's hunger cues if given the appropriate education and support."	T5, S196
"Too often [in decisions regarding oral feeding], developmental cues are ignored. They shouldn't be."	T2, S69
6. NG tubes: Organisation and timing of feeding	
"I think 'time-based' feeding puts the infant at risk more than teaching all staff and family about 'infant driven' or 'cue-based' feeding practices. A baby may feed beautifully for 25 minutes at one feeding, but need to be done after 4 minutes at another feeding."	T2, S88

(*Continued*)

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Table 6. (*Continued*)

Theme quotation	Survey topic and statement
"[Unlimited oral daytime feeding plus continuous night NG feeds] could result in an overly hungry infant during the day that is overly full and sleepy by morning, and there may be a concern for the baby learning hunger/satiation cues."	T2, S89
"I actually agree with [unlimited oral daytime feeding plus continuous night NG feeds] because then the infant gets focused practice with oral feeding."	T2, S89
"This is a difficult question to answer because of the possibility for a great degree of variability in what an infant is able to do during the day and how stable they are."	T2, S89
"This is mostly a style question. I'm not sure it makes any difference nutritionally."	T2, S89
7. NG tubes: Impact on oral feeding development	
"The literature is controversial on [whether NG tubes negatively impact oral feeding development]. Feeding tubes provide a way to get more aggressive nutritional plans executed; with growth comes development. So if the feeding tube provides better growth, there could be earlier feeding success."	T2, S79
"There are multiple studies showing that this [whether NG tubes negatively impact oral feeding development] is not the case."	T2, S79
8. Tube feeding: Ability to mitigate weight loss	
"Some kids need tube feedings no matter how hard the patient and families work at it."	T3, S142
"If you manage the nutritional care plan appropriately, you can meet nutritional needs PO or by feeding tube."	T3, S142
"Not completely mitigate because other non-nutritional factors (e.g., infection) which are common in these kids also reduce growth rates."	T3, S147
"Tube feed supplementation mitigates weight loss. Infants may still experience growth failure, but would experience MORE growth failure without tube feeds."	T3, S147
9. Tube feeding: Impact on caregiver stress	
"G-tubes are inherently stressful due to the additional burden put on parents."	T3, S148
"Parents often say that having the support of a G-tube is less stressful than living with the stress of trying to 'force' an infant to take adequate nutrition."	T3, S148
"It depends on education or support that the parents receive"	T3, S149
"Some parents find relief is not having to fixate on oral volume intake if it is a struggle."	T3, S149
"I think the stress is initially higher but over time, most parents will say that they are relieved to have the feeding tube when it is needed."	T3, S149
"We know this through research - parents experience stress regarding feeding, especially feeding tubes."	
10. NEC: Impact of feeding advancement rates and type of nutrition	
"I agree [that rapid advancement in caloric density may increase the risk of NEC], presuming the fortification of feeds is done with cow's milk-based human milk fortifier."	T3, S121
"This has been thoroughly studied (Cochrane) in preemies who would be at highest risk of NEC (non-CCHD population). Feeding advancement rates are not associated with NEC."	T3, S121
"NEC occurs more commonly with formula than any kind of human milk."	T3, S137
"There is no conclusive data on [whether NEC is more common with formula vs. human milk], and you can find studies that say both things."	T3, S137
"[NEC is more common with formula vs. human milk] is factual based on published evidence."	T3, S137

[a]T = topic; with T1, human milk; T2, developing oral feeding skills; T3, clinical feeding practice; T4, growth failure; T5, parental concern about feeding
[b]S = statement; followed by the number of the statement referred to by the qualitative response. Statement numbers can be found in Supplementary Table S2
CCHD = complex congenital heart disease; CHF = congenital heart failure; G-tube = gastrostomy tube; MOM = mother's own milk; NEC = necrotising enterocolitis; NG = nasogastric; NICU = neonatal intensive care unit; PICU = pediatric intensive care unit; PO = by mouth; REE = resting energy expenditure

who are between stages of surgical palliation (interstage), the literature does not support this theory. Eight of the 12 available studies on this topic found that tube-fed infants with complex CHD experienced reduced weight gain during the interstage period, compared to those who were orally fed.[19,33,72–77] Only one study has demonstrated superior growth in infants who were tube fed.[78] It is probable that feeding tubes allow critically ill infants to maintain a higher rate of growth than they would be able to achieve with oral feeding alone. However, to our knowledge, there is no conclusive evidence that supports this theory in infants with complex CHD, and there is considerable variation in institutional and provider criteria determining the necessity of feeding tubes, especially gastrostomy tubes, in this population.[30,33,79] Future research is needed to more clearly understand how tube feeding affects growth in infants with complex CHD, and to determine best practices in supporting growth and development for infants who are tube fed.

Growth failure

While the topic of growth failure included the lowest percentage of statements reaching consensus, patients offered little explanation for their disparate answer choices. Many statements related to growth failure focused on specific details of a nutritional plan

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(e.g., volume, calories, protein, use of parenteral nutrition). The lack of consensus may reflect the persistent variation in clinical practice for infants with complex CHD.[30,31,33,34,36,80] While there have been recent efforts to create evidence-based feeding protocols for this population,[21,22,43,70,81–84] provider- and centre-specific feeding practice continues to be the norm. A particularly striking example is found in Slicker et al., (2016), in which only 3 out of the 46 (7%) United States of America centres participating in the National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) adopted the NPC-QIC's published guidelines for feeding readiness evaluation after stage 1 palliation.[30] While there is certainly a need for flexibility in tailoring feeding care based on an infant's severity of illness and clinical course, there are considerable benefits associated with feeding protocol implementation.[19,35–37,70] Future research should focus on the development of comprehensive, infant-centred, tailorable feeding protocols for infants with complex CHD, and should examine barriers to protocol adoption.

Implications

The findings from this study can inform practice and provide direction for future research. In regard to practice, clinical interventions focused on supporting human milk and breastfeeding for infants with complex CHD are needed. A model for care that has been tested specifically for infants with complex surgical anomalies[15,24] may be particularly useful to guide practice and increase rates of human milk provision and breastfeeding in this population. Moreover, by linking evidence on feeding infants with complex CHD to practice, findings from this study have the potential to sensitise healthcare providers to areas of miscommunication and uncertainty experienced by their patients. This expanded understanding could allow providers to mitigate stress for family caregivers of infants with complex CHD. Our study findings also highlight key areas where gaps may exist, and suggest five foci for future research: (1) the adequacy of human milk to support growth and the need for supplementation or fortification; (2) the safety and feasibility of breastfeeding for infants with complex CHD; (3) best practices in the use of nasogastric tubes and their potential impact on the development of oral feeding skills; (4) the ability of supplemental tube feeding to mitigate weight loss or facilitate catch-up growth; and (5) prevention and treatment of growth failure.

Strengths and limitations

The use of the modified Delphi method in this study elicited an understanding of consensus and non-consensus through three survey rounds in a relatively short amount of time, without geographical constraints. This method is non-confrontational, which, when compared to face-to-face group discussion, substantially reduces biasing of response and the risk of a single dominant opinion skewing results. Qualitative data were particularly useful for interpreting areas of non-consensus. The major limitation of this study is the relatively small sample size of clinical experts. While the number is adequate for achieving representative consensus,[40] clinical expert responses may not be generalisable to all situations and settings. Additionally, patients were asked to evaluate short statements that were designed to reflect current research findings. It was beyond the scope of this study to offer explanatory context for these statements, which may have helped facilitate greater consensus. Between the second and third rounds of the survey, the coronavirus disease 2019 pandemic caused significant changes to the healthcare system, which may have impacted patient responses in the final round. To account for any historical change, we asked patients if they thought their answers had been affected by the current pandemic (answer choices: "yes," "no," "not sure"). No respondents chose "yes;" therefore, it is unlikely that this survey was impacted by coronavirus disease 2019.

Conclusion

This study identified areas of consensus and non-consensus in regard to evidence-based statements about feeding infants with complex CHD. The results demonstrate strong clinical consensus as to the importance of human milk, but reveal a need for further identification and validation of best practices in managing a human milk diet for these infants. Areas of non-consensus may be particularly prone to variation in practice, and need further development of evidence-based feeding management strategies. Healthcare providers should be sensitive to the potential for miscommunication or uncertainty experienced by families in regard to these topics, and work with a coordinated, interdisciplinary approach to mitigate any psychological distress that could affect these caregivers.

Supplementary material. To view supplementary material for this article, please visit https://doi.org/10.1017/S1047951120004370.

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Conflicts of interest. None.

Ethical standards. Not applicable.

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References

1. Pace ND, Oster ME, Forestieri NE, Enright D, Knight J, Meyer RE. Sociodemographic factors and survival of infants with congenital heart defects. Pediatrics 2018; 142: e20180302. doi: 10.1542/peds.2018-0302
2. Oster ME, Lee KA, Honein MA, Riehle-Colarusso T, Shin M, Correa A. Temporal trends in survival among infants with critical congenital heart defects. Pediatrics 2013; 131: e1502–e1508. doi: 10.1542/peds.2012-3435
3. Gordon BM, Rodriguez S, Lee M, Chang R-K. Decreasing number of deaths of infants with hypoplastic left heart syndrome. J Pediatr 2008; 153: 354–358. doi: 10.1016/j.jpeds.2008.03.009
4. Medoff-Cooper B, Ravishankar C. Nutrition and growth in congenital heart disease: a challenge in children. Curr Opin Cardiol 2013; 28: 122–129. doi: 10.1097/HCO.0b013e32835dd005
5. Floh AA, Slicker J, Schwartz SM. Nutrition and mesenteric issues in pediatric cardiac critical care. Pediatr Crit Care Med 2016; 17 (8 Suppl 1): S243–S249. doi: 10.1097/PCC.0000000000000801
6. Mangili G, Garzoli E, Sadou Y. Feeding dysfunctions and failure to thrive in neonates with congenital heart diseases. Pediatr Med Chir 2018; 40. doi: 10.4081/pmc.2018.196
7. Gaynor JW, Stopp C, Wypij D, et al. Neurodevelopmental outcomes after cardiac surgery in infancy. Pediatrics 2015; 135: 816–825. doi: 10.1542/peds.2014-3825
8. Mitting R, Marino L, Macrae D, Shastri N, Meyer R, Pathan N. Nutritional status and clinical outcome in postterm neonates undergoing surgery for

congenital heart disease. Pediatr Crit Care Med 2015; 16: 448–452. doi: 10.1097/PCC.0000000000000402
9. Radman M, Mack R, Barnoya J, et al. The effect of preoperative nutritional status on postoperative outcomes in children undergoing surgery for congenital heart defects in San Francisco (UCSF) and Guatemala City (UNICAR). J Thorac Cardiovasc Surg 2014; 147: 442–450. doi: 10.1016/j.jtcvs.2013.03.023
10. Eskedal LT, Hagemo PS, Seem E, et al. Impaired weight gain predicts risk of late death after surgery for congenital heart defects. Arch Dis Child 2008; 93: 495–501. doi: 10.1136/adc.2007.126219
11. Ghanayem NS, Allen KR, Tabbutt S, et al. Interstage mortality after the Norwood procedure: results of the multicenter Single Ventricle Reconstruction trial. J Thorac Cardiovasc Surg 2012; 144: 896–906. doi: 10.1016/j.jtcvs.2012.05.020
12. Hartman DM, Medoff-Cooper B. Transition to home after neonatal surgery for congenital heart disease. MCN Am J Matern Nurs 2012; 37: 95–100. doi: 10.1097/NMC.0b013e318241dac1
13. Imms C. Feeding the infant with congenital heart disease: an occupational performance challenge. Am J Occup Ther 2001; 55: 277–284. doi: 10.5014/ajot.55.3.277
14. Tregay J, Wray J, Crowe S, et al. Going home after infant cardiac surgery: A UK qualitative study. Arch Dis Child 2016; 101: 320–325. doi: 10.1136/archdischild-2015-308827
15. Edwards TM, Spatz DL. An innovative model for achieving breast-feeding success in infants with complex surgical anomalies. J Perinat Neonatal Nurs 2010; 24: 246–253. doi: 10.1097/JPN.0b013e3181e8d517
16. Martino K, Wagner M, Froh EB, Hanlon AL, Spatz DL. Postdischarge breastfeeding outcomes of infants with complex anomalies that require surgery. J Obstet Gynecol Neonatal Nurs 2015; 44: 450–457. doi: 10.1111/1552-6909.12568
17. Alves E, Rodrigues C, Fraga S, Barros H, Silva S. Parents' views on factors that help or hinder breast milk supply in neonatal care units: systematic review. Arch Dis Child 2013; 98: F511–F517. doi: 10.1136/archdischild-2013-304029
18. Petit CJ, Fraser CD, Mattamal R, Slesnick TC, Cephus CE, Ocampo EC. The impact of a dedicated single-ventricle home-monitoring program on interstage somatic growth, interstage attrition, and 1-year survival. J Thorac Cardiovasc Surg 2011; 142: 1358–1366. doi: 10.1016/j.jtcvs.2011.04.043
19. Hehir DA, Rudd N, Slicker J, et al. Normal interstage growth after the Norwood operation associated with interstage home monitoring. Pediatr Cardiol 2012; 33: 1315–1322. doi: 10.1007/s00246-012-0320-x
20. Demirci J, Caplan E, Brozanski B, Bogen D. Winging it: Maternal perspectives and experiences of breastfeeding newborns with complex congenital surgical anomalies. J Perinatol 2018; 38: 708–717. doi: 10.1038/s41372-018-0077-z
21. Karpen HE. Nutrition in the cardiac newborns. Clin Perinatol 2016; 43: 131–145. doi: 10.1016/j.clp.2015.11.009
22. Ehrmann DE, Mulvahill M, Harendt S, et al. Toward standardization of care: the feeding readiness assessment after congenital cardiac surgery. Congenit Heart Dis 2018; 13: 31–37. doi: 10.1111/chd.12550
23. Davis JA, Spatz DL. Human milk and infants with congenital heart disease: a summary of current literature supporting the provision of human milk and breastfeeding. Adv Neonatal Care. Published online 2019: 1. doi: 10.1097/ANC.0000000000000582
24. Spatz DL. Ten steps for promoting and protecting breastfeeding for vulnerable infants. J Perinat Neonatal Nurs 2004; 18: 385–396. doi: 10.1097/00005237-200410000-00009
25. Spatz DL. State of the science: use of human milk and breast-feeding for vulnerable infants. J Perinat Neonatal Nurs 2006; 20: 51–55. doi: 10.1097/00005237-200601000-00017
26. Marino BL, O'Brien P, LoRe H. Oxygen saturations during breast and bottle feedings in infants with congenital heart disease. J Pediatr Nurs 1995; 10: 360–364.
27. Combs VL, Marino BL. A comparison of growth patterns in breast and bottle-fed infants with congenital heart disease. Pediatr Nurs 1993; 19: 175–179.
28. Toms R, Jackson KW, Dabal RJ, Reebals CH, Alten JA. Preoperative trophic feeds in neonates with hypoplastic left heart syndrome. Congenit Heart Dis 2015; 10: 36–42. doi: 10.1111/chd.12177
29. Cognata A, Kataria-Hale J, Griffiths P, et al. Human milk use in the preoperative period is associated with a lower risk for necrotizing enterocolitis in neonates with complex congenital heart disease. J Pediatr 2019; 215: 11–16.e2. doi: 10.1016/j.jpeds.2019.08.009
30. Slicker J, Sables-Baus S, Lambert LM, et al. Perioperative feeding approaches in single ventricle infants: a survey of 46 centers. Congenit Heart Dis 2016; 11: 707–715. doi: 10.1111/chd.12390
31. Tume LN, Balmaks R, da Cruz E, et al. Enteral feeding practices in infants with congenital heart disease across European PICUs: A European Society of Pediatric and Neonatal Intensive Care survey. Pediatr Crit Care Med 2018; 19: 137–144. doi: 10.1097/PCC.0000000000001412
32. Howley LW, Kaufman J, Wymore E, et al. Enteral feeding in neonates with prostaglandin-dependent congenital cardiac disease: international survey on current trends and variations in practice. Cardiol Young 2012; 22: 121–127. doi: 10.1017/S1047951111001016
33. Lambert LM, Pike NA, Medoff-Cooper B, et al. Variation in feeding practices following the Norwood procedure. J Pediatr 2014; 164: 237–242.e1. doi: 10.1016/j.jpeds.2013.09.042
34. Alten JA, Rhodes LA, Tabbutt S, et al. Perioperative feeding management of neonates with CHD: Analysis of the Pediatric Cardiac Critical Care Consortium (PC4) registry. Cardiol Young 2015; 25: 1593–1601. doi: 10.1017/S1047951115002474
35. Ehrmann DE, Harendt S, Church J, et al. Noncompliance to a postoperative algorithm using feeding readiness assessments prolonged length of stay at a pediatric heart institute. Pediatr Qual Saf 2017; 2: e042. doi: 10.1097/pq9.0000000000000042
36. Anderson JB, Beekman RH 3rd, Kugler JD, et al. Use of a learning network to improve variation in interstage weight gain after the Norwood operation. Congenit Heart Dis 2014; 9: 512–520. doi: 10.1111/chd.12232
37. Furlong-Dillard JM, Miller BJ, Sward KA, et al. The association between feeding protocol compliance and weight gain following high-risk neonatal cardiac surgery. Cardiol Young 2019; 29: 594–601. doi: 10.1017/S1047951119000222
38. Lambert JM, Watters NE. Breastfeeding the infant/child with a cardiac defect: an informal survey. J Hum Lact 1998; 14: 151–155. doi: 10.1177/089033449801400221
39. Rowe G, Wright G. Expert opinions in forecasting: Role of the Delphi technique. In: Principles of Forecasting: A Handbook for Researchers and Practitioners. Kluwer Academic Publishers, Norwell, MA, 2001: 125–144.
40. Akins RB, Tolson H, Cole BR. Stability of response characteristics of a Delphi panel: application of bootstrap data expansion. BMC Med Res Methodol 2005; 5: 37. doi: 10.1186/1471-2288-5-37
41. Iqbal S, Pipon-Young L. The Delphi method. The Psychologist 2009; 22: 598–601.
42. Miles MB, Huberman AM, Saldaña J. Qualitative Data Analysis: A Methods Sourcebook. 3rd ed. SAGE Publications, Inc, Thousand Oaks, CA, 2014.
43. Slicker J, Hehir DA, Horsley M, et al. Nutrition algorithms for infants with hypoplastic left heart syndrome; birth through the first interstage period. Congenit Heart Dis 2013; 8: 89–102. doi: 10.1111/j.1747-0803.2012.00705.x
44. Sahu MK, Singal A, Menon R, et al. Early enteral nutrition therapy in congenital cardiac repair postoperatively: a randomized, controlled pilot study. Ann Card Anaesth 2016; 19: 653–661. doi: 10.4103/0971-9784.191550
45. Rosti L, Vivaldo T, Butera G, Chessa M, Carlucci C, Giamberti A. Postoperative nutrition of neonates undergoing heart surgery. Pediatr Medica E Chir Med Surg Pediatr 2011; 33: 236–240.
46. Zyblewski SC, Nietert PJ, Graham EM, Taylor SN, Atz AM, Wagner CL. Randomized clinical trial of preoperative feeding to evaluate intestinal barrier function in neonates requiring cardiac surgery. J Pediatr 2015; 167: 47–51.e1. doi: 10.1016/j.jpeds.2015.04.035
47. Lambert DK, Christensen RD, Henry E, et al. Necrotizing enterocolitis in term neonates: Data from a multihospital health-care system. J Perinatol 2007; 27: 437–443.
48. El-Koofy N, Mahmoud AM, Fattouh AM. Nutritional rehabilitation for children with congenital heart disease with left to right shunt. Turk J Pediatr 2017; 59: 442–451. doi: 10.24953/turkjped.2017.04.011
49. Spatz DL. Beyond BFHI: The Spatz 10-Step and breastfeeding resource nurse model to improve human milk and breastfeeding outcomes. J

Perinat Neonatal Nurs 2018; 32: 164–174. doi: 10.1097/JPN.0000000000000339
50. Froh EB, Deatrick JA, Curley MAQ, Spatz DL. Making meaning of pumping for mothers of infants with congenital diaphragmatic hernia. J Obstet Gynecol Neonatal Nurs 2015; 44: 439–449. doi: 10.1111/1552-6909.12564
51. Meier PP, Johnson TJ, Patel AL, Rossman B. Evidence-based methods that promote human milk feeding of preterm infants. Clin Perinatol 2017; 44: 1–22. doi: 10.1016/j.clp.2016.11.005
52. Rendón-Macías ME, Castañeda-Muciño G, Cruz JJ, Mejía-Aranguré JM, Villasís-Keever MA. Breastfeeding among patients with congenital malformations. Arch Med Res 2002; 33: 269–275. doi: 10.1016/S0188-4409(02)00361-2
53. Tandberg BS, Ystrom E, Vollrath ME, Holmstrom H. Feeding infants with CHD with breast milk: Norwegian Mother and Child Cohort Study. Acta Paediatr Oslo Nor 1992 2010; 99: 373–378. doi: 10.1111/j.1651-2227.2009.01605.x
54. Boctor DL, Pillo-Blocka F, McCrindle BW. Nutrition after cardiac surgery for infants with congenital heart disease. Nutr Clin Pract 1999; 14: 111–115. doi: 10.1177/088453369901400303
55. Fugate K, Hernandez I, Ashmeade T, Miladinovic B, Spatz DL. Improving human milk and breastfeeding practices in the NICU. J Obstet Gynecol Neonatal Nurs 2015; 44: E14–E15. doi: 10.1111/1552-6909.12566
56. McCrary AW, Clabby ML, Mahle WT. Patient and practice factors affecting growth of infants with systemic-to-pulmonary shunt. Cardiol Young 2013; 23: 499–506. doi: 10.1017/S1047951112001382
57. Spatz DL, Schmidt KJ, Kinzler S. Implementation of a human milk management center. Adv Neonatal Care 2014; 14: 253–261. doi: 10.1097/ANC.0000000000000084
58. Spatz DL. Innovations in the provision of human milk and breastfeeding for infants requiring intensive care. J Obstet Gynecol Neonatal Nurs 2012; 41: 138–143. doi: 10.1111/j.1552-6909.2011.01315.x
59. Meier P, Anderson GC. Responses of small preterm infants to bottle- and breast-feeding. MCN Am J Matern Nurs 1987; 12: 97–105. doi: 10.1097/00005721-198703000-00006
60. Chen C-H, Wang T-M, Chang H-M, Chi C-S. The effect of breast-and bottle-feeding on oxygen saturation and body temperature in preterm infants. J Hum Lact 2000; 16: 21–27. doi: 10.1177/089033440001600105
61. Spence K, Swinsburg D, Griggs J-A, Johnston L. Infant well-being following neonatal cardiac surgery. J Clin Nurs 2011; 20: 2623–2632. doi: 10.1111/j.1365-2702.2011.03716.x
62. Barbas KH, Kelleher DK. Breastfeeding success among infants with congenital heart disease. Pediatr Nurs 2004; 30: 285–289.
63. Wallis M, Harper M. Supporting breastfeeding mothers in hospital: Part 2b. Paediatr Nurs 2007; 19: 20–23.
64. Medoff-Cooper B, Naim M, Torowicz D, Mott A. Feeding, growth, and nutrition in children with congenitally malformed hearts. Cardiol Young 2010; 20 (S3): 149–153. doi: 10.1017/S1047951110001228
65. Steltzer MM, Sussman-Karten K, Kuzdeba HB, Mott S, Connor JA. Creating opportunities for optimal nutritional experiences for infants with complex congenital heart disease. J Pediatr Health Care 2016; 30: 599–605. doi: 10.1016/j.pedhc.2016.08.002
66. Owens B. Breastfeeding an infant after heart transplant surgery. J Hum Lact 2002; 18: 53–55.
67. Torowicz DL, Seelhorst A, Froh EB, Spatz DL. Human milk and breastfeeding outcomes in infants with congenital heart disease. Breastfeed Med 2015; 10: 31–37. doi: 10.1089/bfm.2014.0059
68. Gregory C. Use of test weights for breastfeeding infants with congenital heart disease in a cardiac transitional care unit: a best practice implementation project. JBI Database Syst Rev Implement Rep 2018; 16: 2224–2245. doi: 10.11124/JBISRIR-2017-003759
69. Premji SS, Chessell L. Continuous nasogastric milk feeding versus intermittent bolus milk feeding for premature infants less than 1500 grams. Cochrane Neonatal Group, ed. *Cochrane Database Syst Rev*. Published online November 9, 2011. doi: 10.1002/14651858.CD001819.pub2
70. Furlong-Dillard J, Neary A, Marietta J, et al. Evaluating the impact of a feeding protocol in neonates before and after biventricular cardiac surgery. Pediatr Qual Saf 2018; 3: e080. doi: 10.1097/pq9.0000000000000080
71. Taylor AM, Cloherty M, Alexander J, Holloway I, Galvin K, Inch S. Parental distress around supplementing breastfed babies using nasogastric tubes on the post-natal ward: a theme from an ethnographic study. Matern Child Nutr 2009; 5: 117–124. doi: 10.1111/j.1740-8709.2008.00165.x
72. Di Maria MV, Glatz AC, Ravishankar C, et al. Supplemental tube feeding does not mitigate weight loss in infants with shunt-dependent single-ventricle physiology. Pediatr Cardiol 2013; 34: 1350–1356. doi: 10.1007/s00246-013-0648-x
73. Williams RV, Zak V, Ravishankar C, et al. Factors affecting growth in infants with single ventricle physiology: a report from the Pediatric Heart Network Infant Single Ventricle Trial. J Pediatr 2011; 159: 1017–22.e2. doi: 10.1016/j.jpeds.2011.05.051
74. Hoch JM, Fatusin O, Yenokyan G, Thompson WR, Lefton-Greif MA. Feeding methods for infants with single ventricle physiology are associated with length of stay during stage 2 surgery hospitalization. Congenit Heart Dis 2019; 14: 438–445. doi: 10.1111/chd.12742
75. Anderson JB, Beekman RH, Border WL, et al. Lower weight-for-age z score adversely affects hospital length of stay after the bidirectional Glenn procedure in 100 infants with a single ventricle. J Thorac Cardiovasc Surg 2009; 138: 397–404.e1. doi: 10.1016/j.jtcvs.2009.02.033
76. Medoff-Cooper B, Irving SY, Marino BS, et al. Weight change in infants with a functionally univentricular heart: from surgical intervention to hospital discharge. Cardiol Young 2011; 21: 136–144. doi: 10.1017/S104795111000154X
77. Uzark K, Wang Y, Rudd N, et al. Interstage feeding and weight gain in infants following the Norwood operation: can we change the outcome? Cardiol Young 2012; 22: 520–527. doi: 10.1017/S1047951111002083
78. Ciotti G, Holzer R, Pozzi M, Dalzell M. Nutritional support via percutaneous endoscopic gastrostomy in children with cardiac disease experiencing difficulties with feeding. Cardiol Young 2002; 12: 537–541. doi: 10.1017/S1047951102000975
79. Hill GD, Hehir DA, Bartz PJ, et al. Effect of feeding modality on interstage growth after stage I palliation: a report from the National Pediatric Cardiology Quality Improvement Collaborative. J Thorac Cardiovasc Surg 2014; 148: 1534–1539. doi: 10.1016/j.jtcvs.2014.02.025
80. Simsic JM, Carpenito K-R, Kirchner K, et al. Reducing variation in feeding newborns with congenital heart disease. Congenit Heart Dis 2017; 12: 275–281. doi: 10.1111/chd.12435
81. del Castillo SL, McCulley ME, Khemani RG, et al. Reducing the incidence of necrotizing enterocolitis in neonates with hypoplastic left heart syndrome with the introduction of an enteral feed protocol. Pediatr Crit Care Med. Published online October 2009:1. doi: 10.1097/PCC.0b013e3181c01475
82. Manuri L, Morelli S, Agati S, et al. Early hybrid approach and enteral feeding algorithm could reduce the incidence of necrotising enterocolitis in neonates with ductus-dependent systemic circulation. Cardiol Young 2017; 27: 154–160. doi: 10.1017/S1047951116000275
83. Newcombe J, Fry-Bowers E. A post-operative feeding protocol to improve outcomes for neonates with critical congenital heart disease. J Pediatr Nurs 2017; 35 (jns, 8607529): 139–143. doi: 10.1016/j.pedn.2016.12.010
84. Braudis NJ, Curley MAQ, Beaupre K, et al. Enteral feeding algorithm for infants with hypoplastic left heart syndrome poststage I palliation. Pediatr Crit Care Med 2009; 10: 460–466. doi: 10.1097/PCC.0b013e318198b167