



Feeding Variation Among Infants in Acute Care Cardiology Units

Adam L. Ware¹ · Courtney Jones² · Alaina K. Kipps³ · Lara Khadr⁴ · Elisa Marcuccio⁵ · Sonali S. Patel⁶ · Sarah Plummer⁷ · Chitra Ravishankar⁸ · Mayte Figueroa⁹

Received: 12 January 2024 / Accepted: 4 June 2024

© The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2024

Abstract

Infants with heart disease are at high risk of feeding difficulties and complications. Feeding practices amongst acute care cardiology units are not standardized. This study aims to describe feeding practices for infants at the time of discharge from a Pediatric Acute Care Cardiology Collaborative (PAC³) center and practice variation between centers. Discharge encounters for infants in the PAC³ registry between February 2019 and October 2021 were included. Nutrition type and feeding route at discharge were summarized with descriptive statistics and a modified bump plot. Center variation was assessed using funnel plots with control limits set at the 99.9% confidence interval from the group mean. A total of 15,414 encounters across 24 PAC³ centers were recorded from 8313 unique patients (median encounters 1, range 1–25). Nutrition at discharge consisted of standard formula in 8368 (54%), human milk in 6300 (41%), and elemental formula in 3230 (21%), either alone or in combination. Feeds were fortified to ≥ 24 kcal/oz in 12,359 (80%). Discharge supplemental tube feeding was present in 7353 (48%) encounters with 4643 (63%) receiving continuous feeds, 2144 (29%) bolus feeds, and 566 (8%) a combination. Funnel plots demonstrated variability in nutrition type and feeding route at discharge. Infants with heart disease commonly require high calorie nutrition and supplemental tube feedings at discharge. Feeding strategies at discharge vary widely between PAC³ centers. Collaborative approaches to identify best practices in feeding strategies are needed.

Keywords Congenital heart disease · Inpatient · Nutrition · Infants

Introduction

Infants with congenital heart disease are at high risk of feeding difficulties and complications in the neonatal period both before and after surgical intervention. Feeding challenges may begin prior to surgery due to altered hemodynamics,

high metabolic demand, necrotizing enterocolitis, gastroesophageal reflux, and other genetic and endocrine factors [1–3]. In addition, several commonly used medical therapies such as prostaglandins and positive-pressure respiratory support may affect provider comfort with oral and enteral feeding. Surgical repair including the necessary intubation,

✉ Adam L. Ware
adam.ware@hsc.utah.edu

¹ Division of Pediatric Cardiology, Department of Pediatrics, University of Utah, 81 N. Mario Capecchi Dr, Salt Lake City, UT 84113, USA

² Acute Care Therapy Services, Primary Children's Hospital, Salt Lake City, Utah, USA

³ Division of Pediatric Cardiology, Department of Pediatrics, Stanford University, Palo Alto, CA, USA

⁴ University of Michigan Congenital Heart Center, C.S. Mott Children's Hospital, Ann Arbor, MI, USA

⁵ Division of Pediatric Cardiology, Department of Pediatrics, University of Cincinnati College of Medicine, Cincinnati, OH, USA

⁶ Division of Pediatric Cardiology, Department of Pediatrics, University of Texas Southwestern Medical Center, Dallas, TX, USA

⁷ Division of Pediatric Cardiology, Department of Pediatrics, Case Western Reserve University, Cleveland, OH, USA

⁸ Division of Cardiology, Department of Pediatrics, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA, USA

⁹ Division of Pediatric Cardiology, Department of Pediatrics, Washington University School of Medicine, St. Louis, MS, USA

transesophageal echocardiogram, and cardiopulmonary bypass may further contribute to feeding issues. Post-operative complications including necrotizing enterocolitis, vocal cord dysfunction, dysphagia, aspiration, and oral aversion are common and further contribute to feeding challenges [2, 4–8]. Center specific interventions have been implemented to minimize feeding risks in acute care settings [2, 5, 8, 9]. These interventions focus on timing and type of nutrition before and after surgery, most commonly in the cardiac intensive care setting. Most recommendations are based on single center experience. Many patients continue to require nutritional support, including supplemental feeding strategies, throughout their hospitalization and at the time of discharge from the hospital. There are little data regarding practice variation and best practices in nutrition therapy at the time of discharge.

The Pediatric Acute Care Cardiology Collaborative (PAC³) collects detailed feeding data on all infants admitted to an acute care cardiology unit in hospitals throughout the US and Canada. The objective of this study is to describe variation in feeding practices for infants discharged from PAC³ centers.

Methods

All data were obtained from centers participating in PAC³. PAC³ is a quality improvement collaborative that collects data on all patients with primary cardiac disease admitted to the acute care cardiology units of participating centers. PAC³ maintains a clinical registry to support research and quality improvement initiatives [10, 11]. Trained data managers collect and enter data in accordance with the standardized PAC³ Data Definitions Manual. The PAC³ registry shares common terminology and definitions with applicable data points from the Pediatric Cardiac Critical Care Consortium, International Pediatric and Congenital Cardiac Code, Society of Thoracic Surgeons Congenital Heart Surgery Database and American College of Cardiology Improving Pediatric and Adult Congenital Treatment Registry. Participating centers are audited on a regular schedule, and audit results suggest complete, accurate, and timely submission of data across centers, with the most recent results demonstrating a major discrepancy rate of 0.12–1.14% across 295 mandatory fields. Only centers that have been audited can contribute data for analysis. The University of Michigan Institutional Review Board provides oversight for the PAC³ Data Coordinating Center; this study was reviewed and approved with waiver of informed consent.

All infants in the PAC³ registry between February 2019 and October 2021 that were discharged from a PAC³ hospitalization prior to 1 year of age were included. For each hospitalization, only data from the final acute care unit stay

preceding discharge were collected. For patients with multiple hospitalizations, each discharge encounter was included. Age < 1 year was chosen due to higher feeding challenges in this age group and the availability of additional feeding data for this age group in the PAC³ registry.

Nutrition variables collected at discharge included: nutrition type (human milk, standard formula, elemental formula), caloric fortification at discharge (≥ 24 kcal/oz), caloric intake at discharge (kcal/kg/day), feeding route [oral, nasogastric tube, gastric tube, and other (post-pyloric or TPN)] and feeding rate (bolus, continuous, or both). Nutrition at discharge was summarized with descriptive statistics including chi squared comparison between groups. Center variation was assessed using funnel plots with control limits set at the 99.9% confidence interval from the group mean. Funnel plots demonstrate control limits based on the group mean and center specific volume. Centers that fall outside of the confidence interval are 3.3 standard deviations from the group mean [12]. Center variation was assessed for nutrition type at discharge and feeding route at discharge. Changes in discharge feeding route over age ranges were demonstrated using a modified bump plot analysis. This analysis demonstrates monthly frequency of each feeding route at discharge by counting the total number of discharges for each feeding route by month and ordering them from most common on top to least common on bottom.

Results

At the time of the analysis 24 PAC³ centers were contributing data. A total of 15,414 encounters were recorded from 8313 unique patients (median encounters 1, range 1–25). Demographic and clinical variables are summarized in Table 1. Nutrition at discharge consisted of standard formula in 8368 (54%), human milk in 6300 (41%), and elemental formula in 3230 (21%), either alone or in combination. Feeds were fortified to ≥ 24 kcal/oz in 12,359 (80%) and were unfortified (20 kcal/oz) in 2087 (14%). The median caloric intake for patients less than 1 month was 111 kcal/kg/day (IQR 99, 122), for patients between 1–3 months 109 kcal/kg/day (IQR 96, 120) and for patients 3–6 months 97 kcal/kg/day (IQR 82, 112). Patients were discharged on supplemental tube feeds in 7,353 (48%) of encounters. Supplemental tube feeds were gastric in 6723 (91%) and post pyloric in 630 (9%). Of patients discharged with feeding tubes, 4,643 (63%) received continuous feeds, 2,144 (29%) bolus feeds, and 566 (8%) a combination.

Variation in discharge nutrition type by center are demonstrated in Fig. 1. For the entire cohort 41% of patients were discharged on human milk with a range of 20–61%. A total of 11 (46%) centers were outside the 99.9% confidence interval for the group mean. The group mean for

Table 1 Patient demographics

Demographic	n = 15,414 (%)
Sex	
Male	8632 (56)
Female	6782 (44)
Age at Encounter Start	
0–30 days	3239 (21)
31–90 days	3726 (24)
91–180 days	4647 (30)
> 180 days	3802 (25)
Race	
White	9175 (60)
Black	2278 (15)
Multiracial	1697 (11)
Asian	456 (3)
Native American	96 (1)
Not stated	1712 (11)
Ethnicity	2253 (9)
Hispanic/Latino	
Premature	2904 (19)
Syndrome Present	4289 (28)
Encounter Type	
Medical	6424 (42)
Surgical	8990 (58)
Benchmark Operation	
One Ventricle	1657 (11)
Two Ventricles	3433 (22)
Weight for age Z-score at discharge	Mean (SD)
0–30 days	-0.94 (2.63)
31–90 days	-2.02 (1.82)
91–180 days	-1.97 (2.07)
> 180 days	-1.51 (1.56)

discharge on standard formula at discharge was 54% (range: 41–83%) with 12 (50%) centers falling outside 99.9% confidence intervals. The group mean for elemental formula at discharge was 21% (range: 3–40%) with 13 (54%) centers outside the 99.9% confidence interval.

Impact of patient characteristics on feeding route at discharge are summarized in Table 2. Patients with prematurity, syndromes, and single ventricle heart diseases had higher proportions of nasogastric and gastric feeding tubes at discharge. Variation in discharge feeding route by center are demonstrated in Fig. 2. The group mean for oral feeding only at discharge was 48% (range: 35–78%) with 10 (42%) centers falling above or below the 99.9% confidence interval. The group mean for nasogastric tube feeding only at discharge was 36% (range: 7–55%) with 19 (79%) centers falling outside the 99.9% confidence intervals. The group mean for gastrostomy tube feeding only at discharge was 13% (range: 4–32%) with 16 (67%) centers falling outside

the 99.9% confidence interval. Feeding route at discharge did vary based on age as demonstrated in Fig. 3. The most common feeding route at discharge is oral for all ages, but the second most common feeding route at discharge transitions from nasogastric and oral feeds combined to nasogastric only by 3 months of age and then to gastric tube only by 7 months of age.

Discussion

Appropriate nutrition is essential for infants with heart disease. However, despite the importance of adequate nutrition in this population and known morbidity and mortality related to feeding challenges, we demonstrate that within acute care cardiology units there is no clear standard for nutritional support. Wide practice variation currently exists between centers with respect to the type of nutrition at discharge and the route of feeding at discharge. While the results of this analysis demonstrate practice variability between centers, it does not evaluate which of these feeding practices is associated with the best outcomes. Our analysis evaluated centers based on the group mean and 99.9% confidence intervals based on the number of encounters. This was an arbitrary cutoff to demonstrate the variation between centers. For each of the variables evaluated the “ideal” is unknown and therefore the measurement is not meant to act as a recommendation. Demonstrating practice variability between centers is the first step in PAC³'s effort to establish feeding guidelines for infants with heart disease. A feeding workgroup within the registry has been established to study feeding variability and outcomes within the collaborative. It is feasible to measure the impact of inpatient feeding practice on inpatient feeding complications such as NEC and outcomes such as hospital length of stay and these analyses have been done in some settings [8, 13, 14]. Registries, including PAC³, are currently working to answer these questions as well. However, a more challenging question is how each of these feeding practices impacts children and families in the outpatient setting. The importance of nutrition and weight gain in infants with congenital heart disease has been demonstrated to improve outcomes; particularly in the single ventricle population [5]. The means to achieve optimal weight gain are not standardized and our data demonstrate the ongoing variability between centers. Each feeding method, particularly the feeding route, has considerable implications for the caregivers of children with congenital heart disease. Optimizing safe and adequate enteral feeding is commonly one of the final medical indications for cardiac patients to require hospital care [15], and waiting for children to achieve full oral feeds may prolong the hospital stay. Earlier discharge utilizing nasogastric or gastrostomy tubes places additional stress and anxiety on parents and may be associated with

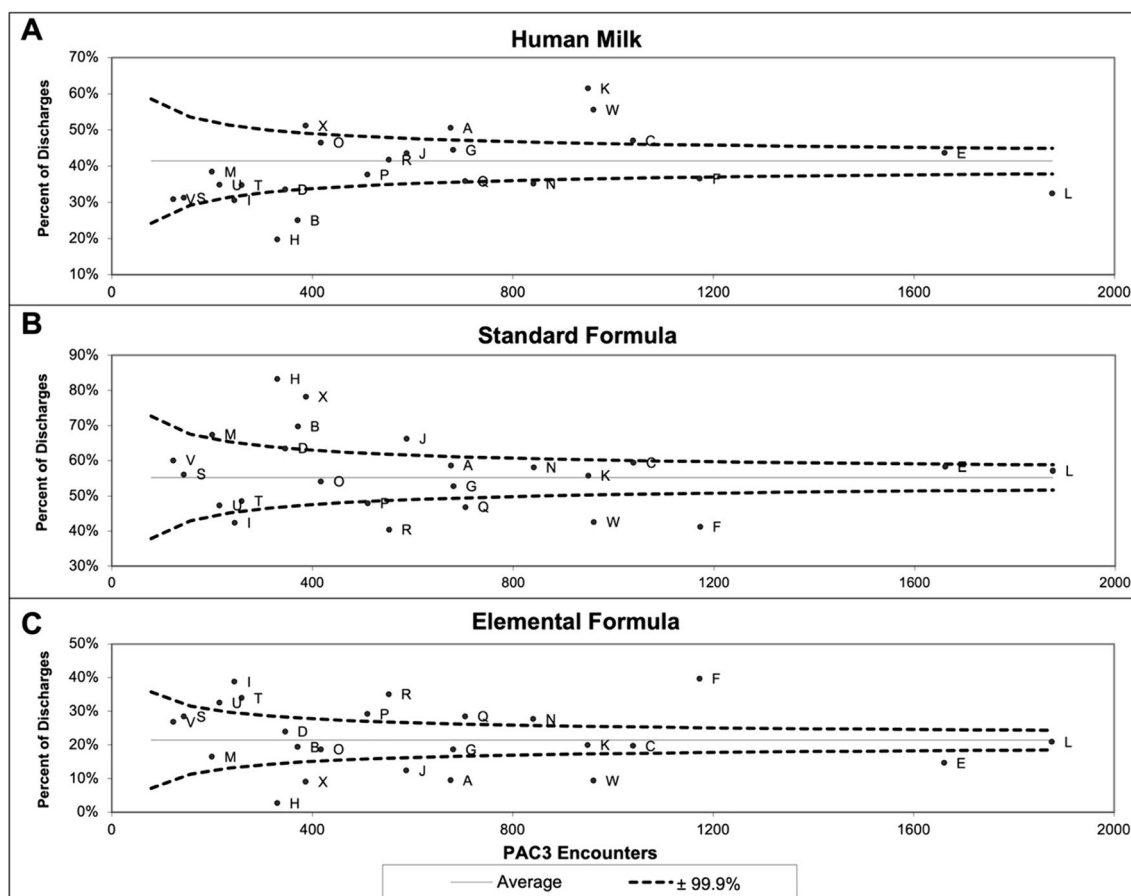


Fig. 1 Funnel Plot demonstrating variation in nutrition type at discharge from Pediatric Acute Care Cardiology Collaborative (PAC³) centers by **A** human milk only, **B** standard formula only, **C** elemental formula only. Center line is group mean with dashed lines representing the $\pm 99.9\%$ confidence interval (± 3.3 standard deviations). Fun-

nel plots account for sample size of individual centers. The data are displayed in an increasing order of center volume. As small sample sizes have the largest variability, the control limits are wide on the left side and become narrower toward the right, as sample size increases

complications [16]. Feeding methods to achieve appropriate weight gain are a high priority for families participating in the PAC³ registry, and our Parent and Family Advocacy Committee consistently list standardization of feeding as a high priority for improvement work. Unfortunately, the lack of a clear best practice limits the direction of improvement efforts in this area. Additionally, inpatient registries such as PAC³ are well suited to measure inpatient complications, but the longitudinal impact of outpatient feeding practices is not easily captured and would require additional data. We did attempt to utilize subsequent hospitalizations within the first year of life to demonstrate the impact of feeding route at discharge, but the heterogeneity of the population and lack

of additional data points for most encounters made this challenging. The modified bump plot is included to demonstrate the impact of age on feeding route at discharge. The shift in the most common methods of feeding toward permanent feeding tubes is most likely representative of a higher complexity patient population that requires multiple hospitalizations and is biased toward the sickest patients. However, future work directed at early identification of clinical variables in our cohort that predict gastrostomy tube insertion during the first year of life may expedite permanent feeding tube placement especially for centers that use these tubes less commonly.

Table 2 Patient Characteristics and Feeding Route at Discharge

Variable	n (N=15,414)	Oral Only	Nasogastric Only	Gastrostomy Tube Only	P value
Sex					<0.001
Male	8632	4268 (49.4)	1156 (13.4)	762 (8.8)	
Female	6782	3060 (45.1)	1037 (15.3)	712 (10.5)	
Age at Encounter Start					<0.001
0–30 days	3239	2067 (63.8)	278 (8.6)	13 (0.4)	
31–90 days	3726	1603 (43.0)	636 (17.1)	218 (5.9)	
91–180 days	4647	2147 (46.2)	778 (16.7)	528 (11.4)	
> 180 days	3802	1511 (39.7)	501 (13.2)	715 (18.8)	
Race					<0.001
White	9175	4309 (47.0)	1347 (14.7)	899 (9.8)	
Black	2278	1101 (48.3)	329 (14.4)	223 (9.8)	
Multiracial	1697	723 (42.6)	225 (13.3)	182 (10.7)	
Asian	456	211 (46.2)	77 (16.9)	33 (7.2)	
Ethnicity					<0.001
Hispanic/Latino	2253	1014 (45.0)	334 (14.8)	245 (10.9)	
Not Hispanic/Latino	11,194	5231 (46.7)	1659 (14.8)	1061 (9.5)	
Gestational Age					<0.001
Premature	2904	1,111 (38.3)	483 (16.6)	404 (13.9)	
Full Term	12,309	6077 (49.4)	1697 (13.8)	1058 (8.6)	
Syndrome					<0.001
Present	4289	1449 (33.8)	783 (18.3)	656 (15.3)	
None	11,124	5879 (52.9)	1409 (12.7)	818 (7.4)	
Benchmark Operation					<0.001
One Ventricle	1657	514 (31.0)	346 (20.9)	195 (11.8)	
Two Ventricle	3433	1968 (57.3)	401 (11.7)	199 (5.8)	

Percentages are calculated by row. Categories do not add up to total N based on inclusion of only listed feeding routes

Limitations

As stated earlier, this study does not demonstrate outcomes related to the feeding practices evaluated. Comparisons between groups are intentionally limited in scope and additional analyses are necessary to fully understand patient variables that may impact feeding decisions at discharge. The data in this manuscript are limited to the acute care setting and do not evaluate factors related to the intensive care unit course. Data are limited to inpatient data and there is not currently an ability to evaluate the impact of various feeding strategies in the outpatient setting. Longitudinal data requires repeat inpatient admissions and are biased toward sicker patients.

Conclusion

Infants with heart disease discharged from an acute care unit commonly require high calorie nutrition and supplemental tube feedings. Variations in nutrition type and utilization of nasogastric and gastrostomy tubes vary widely between PAC³ centers. Collaborative approaches to identify best practices in feeding strategies for children with congenital heart disease are needed.

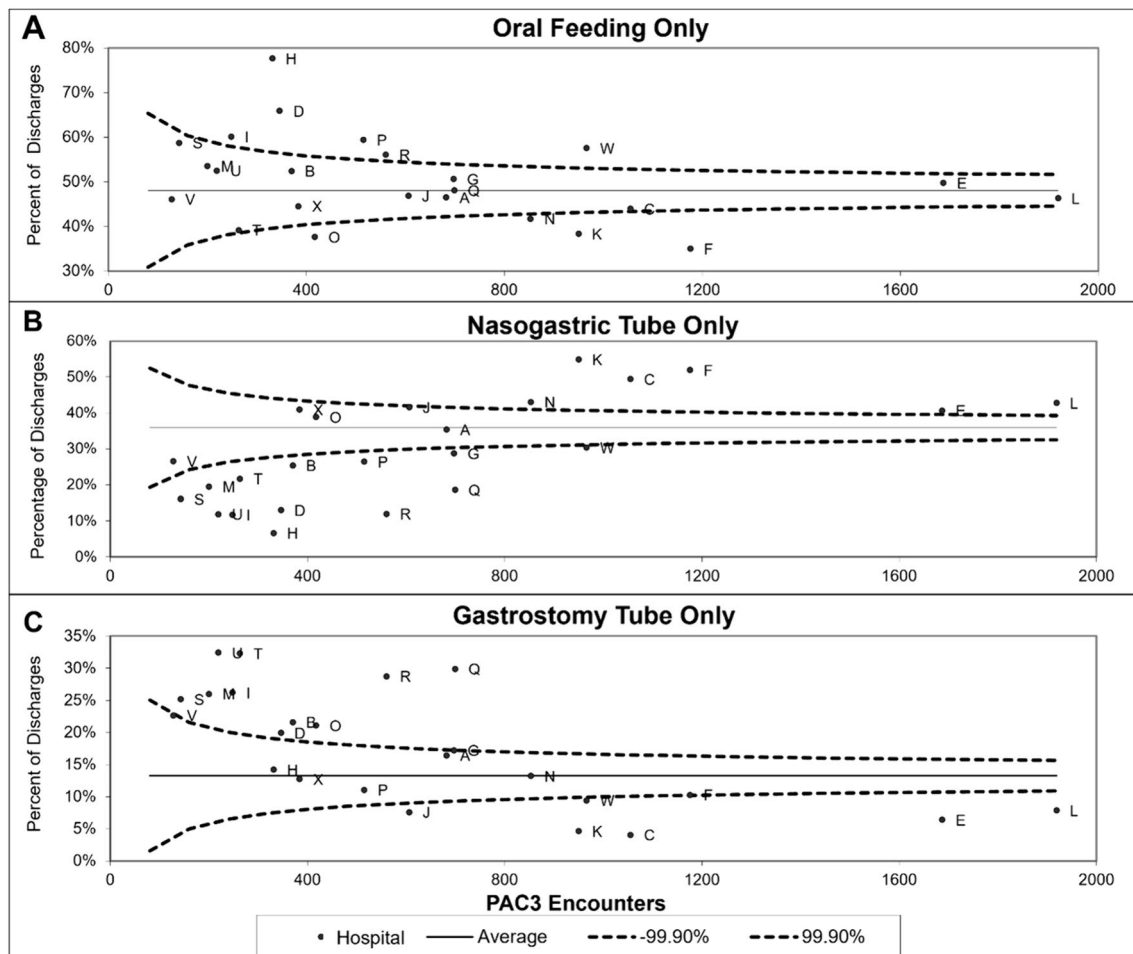
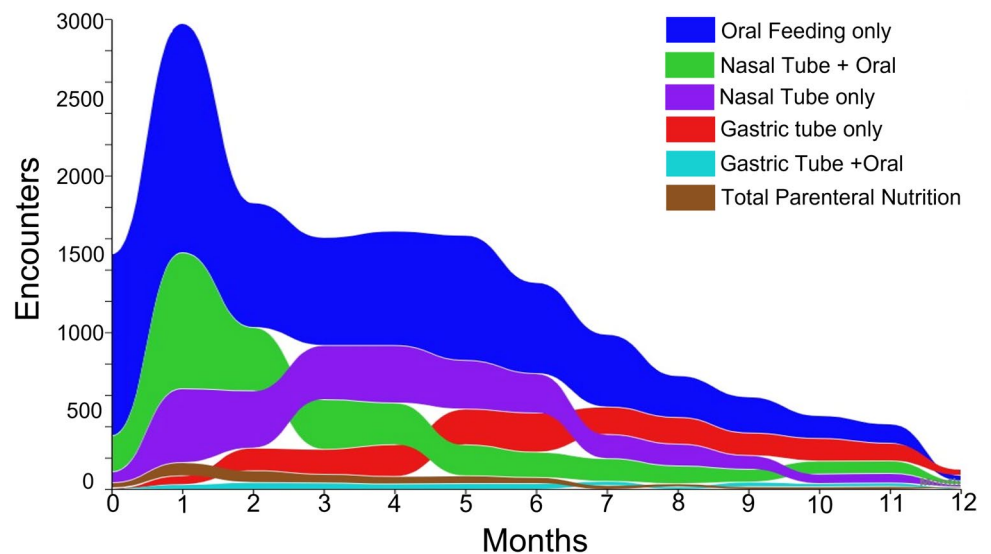


Fig. 2 Funnel Plot demonstrating variation in feeding route at discharge from Pediatric Acute Care Cardiology Collaborative (PAC³) centers by **A** oral feeding only, **B** nasogastric tube feeding only, **C** gastrostomy tube feeding only. Center line is group mean with dashed lines representing the $\pm 99.9\%$ confidence interval (± 3.3 standard

deviations). Funnel plots account for sample size of individual centers. The data are displayed in an increasing order of center volume. As small sample sizes have the largest variability, the control limits are wide on the left side and become narrower toward the right, as sample size increases

Fig. 3 The modified bump plot demonstrates types of feeding route at encounter discharge each month. At each month mark, the color depicting feeding routes are organized in descending order from most frequent (top) to least frequent (bottom)



Author contributions A.W. and M.F. conceptualized and designed the study, lead study meetings, assisted with data collection and analysis, wrote the first draft of the manuscript, and critically reviewed and revised the manuscript. S.P. and L.K. led data collection and assisted with data analysis. All authors assisted with study design and data analysis, participated in study meetings, and each critically reviewed and revised the manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Funding No funding was received for conducting this study.

Declarations

Competing interests The authors declare no competing interests.

Conflict of interest The authors declare they have no relevant financial or non-financial interests to disclose.

References

- Lim CYS, Lim JKB, Moorakonda RB et al (2019) The impact of pre-operative nutritional status on outcomes following congenital heart surgery. *Front Pediatr*. <https://doi.org/10.3389/fped.2019.00429>
- Alten JA, Rhodes LA, Tabbutt S et al (2015) Perioperative feeding management of neonates with CHD: analysis of the pediatric cardiac critical care consortium (PC 4) registry. *Cardiol Young* 25(8):1593–1601. <https://doi.org/10.1017/S1047951115002474>
- Gakenheimer-Smith L, Glotzbach K, Ou Z et al (2019) The impact of neurobehavior on feeding outcomes in neonates with congenital heart disease. *J Pediatr* 214:71–78.e2. <https://doi.org/10.1016/j.jpeds.2019.06.047>
- Kohr LM, Dargan M, Hague A et al (2003) The incidence of dysphagia in pediatric patients after open heart procedures with transesophageal echocardiography. *Ann Thorac Surg* 76(5):1450–1456. [https://doi.org/10.1016/s0003-4975\(03\)00956-1](https://doi.org/10.1016/s0003-4975(03)00956-1)
- Del Castillo SL, McCulley ME, Khemani RG, Jeffries HE, Thomas DW, Peregrine J, Wells WJ, Starnes VA, Moromisato DY (2010) Reducing the incidence of necrotizing enterocolitis in neonates with hypoplastic left heart syndrome with the introduction of an enteral feed protocol. *Pediatric Critical Care Med* 11(3):373–377
- Jones CE, Desai H, Fogel JL et al (2021) Disruptions in the development of feeding for infants with congenital heart disease. *Cardiol Young* 31(4):589–596. <https://doi.org/10.1017/S1047951120004382>
- Iannucci GJ, Oster ME, Mahle WT (2013) Necrotising enterocolitis in infants with congenital heart disease: the role of enteral feeds. *Cardiol Young* 23(4):553–559. <https://doi.org/10.1017/S1047951112001370>
- del Castillo SL, McCulley ME, Khemani RG et al (2010) Reducing the incidence of necrotizing enterocolitis in neonates with hypoplastic left heart syndrome with the introduction of an enteral feed protocol. *Pediatr Crit Care* 11(3):373–377. <https://doi.org/10.1097/PCC.0b013e3181c01475>
- Marino LV, Johnson MJ, Hall NJ et al (2018) The development of a consensus-based nutritional pathway for infants with CHD before surgery using a modified Delphi process. *Cardiol Young* 28(7):938–948. <https://doi.org/10.1017/S1047951118000549>
- Kipps AK, Cassidy SC, Strohacker CM et al (2018) Collective quality improvement in the paediatric cardiology acute care unit: establishment of the pediatric acute care cardiology collaborative (PAC3). *Cardiol Young* 28(8):1019–1023. <https://doi.org/10.1017/S1047951118000811>
- Khadr L, Hart SA, Schachtner S et al (2022) Paediatric acute care cardiology collaborative data registry validation. *Cardiol Young* 32(11):1814–1819. <https://doi.org/10.1017/S1047951121005047>
- Verburg IW, Holman R, Peek N, Abu-Hanna A, de Keizer NF (2018) Guidelines on constructing funnel plots for quality indicators: a case study on mortality in intensive care unit patients. *Stat Method Med Res* 27(11):3350–3366. <https://doi.org/10.1177/0962280217700169>
- Pierick AR, Pierick TA, Reinking BE (2020) Comparison of growth and feeding method in infants with and without genetic abnormalities after neonatal cardiac surgery. *Cardiol Young* Published online. <https://doi.org/10.1017/S1047951120002887>
- Piggott KD, Babb J, Yong S et al (2018) Risk Factors for gastrostomy tube placement in single ventricle patients following the norwood procedure. *Semin Thorac Cardiovasc Surg* 30(4):443–447. <https://doi.org/10.1053/j.semctvs.2018.02.012>
- Ware AL, Reiter L, Winder M, Kelly D, Marietta J, Ohsiek S, Ou Z, Presson A, Bailly DK (2023) The final hospital need in children discharged from a cardiology acute care unit: a single-centre survey study. *Cardiol Young* 10:1967–1974
- Pedersen SD, Parsons HG, Dewey D (2004) Stress levels experienced by the parents of enterally fed children. *Child Care Health Dev* 30(5):507–513. <https://doi.org/10.1111/j.1365-2214.2004.00437.x>

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Springer Nature or its licensor (e.g. a society or other partner) holds exclusive rights to this article under a publishing agreement with the author(s) or other rightsholder(s); author self-archiving of the accepted manuscript version of this article is solely governed by the terms of such publishing agreement and applicable law.