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Symptoms of problematic feeding in children with CHD compared to healthy peers

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Original Article

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Abstract

Children with CHD often experience difficulty with oral feeding, which contributes to growth faltering in this population. Few studies have explored symptoms of problematic feeding in children with CHD using valid and reliable measures of oral feeding. The purpose of this study was to describe symptoms of problematic feeding in children with CHD compared to healthy children without medical conditions, taking into account variables that may contribute to symptoms of problematic feeding. Oral feeding was measured by the Pediatric Eating Assessment Tool, a parent report assessment of feeding with evidence of validity and reliability. This secondary analysis used data collected from web-based surveys completed by parents of 1093 children between 6 months and 7 years of age who were eating solid foods by mouth. General linear models were used to evaluate the differences between 94 children with CHD and 999 children without medical conditions based on the Pediatric Eating Assessment Tool total score and four subscale scores. Covariates tested in the models included breathing tube duration, type of CHD, gastroesophageal reflux, genetic disorder, difficulty with breast- or bottle-feeding during infancy, cardiac surgery, and current child age. Children with CHD had significantly more symptoms of problematic feeding than healthy children on the Pediatric Eating Assessment Tool total score, more physiologic symptoms, problematic mealtime behaviours, selective/restrictive eating, and oral processing dysfunction ($p < 0.001$ for all), when taking into account relevant covariates. Additional research is needed in children with CHD to improve risk assessment and develop interventions to optimise feeding and growth.

Infants and young children with CHD frequently experience difficulty with oral feeding.[1–4] Although there are multiple factors that contribute to growth in this population,[5] difficulty with oral feeding is one of the contributing factors to the high rates of growth faltering and malnutrition that are seen in this group of children.[6,7] Feeding has also been reported as one of the most significant sources of stress and anxiety for parents of children with CHD.[8,9] The presence of feeding difficulties and growth faltering in these children is well documented, but our understanding of the specific underlying aetiologies of these difficulties, the unique problems that these children have with oral feeding, and our ability to determine risk for long-term feeding problems remains very limited.

The studies that have been conducted on feeding outcomes in infants and children with CHD have been limited by a lack of valid and reliable tools for the assessment of oral feeding. Instead, clinical outcomes have been used to define problematic feeding, such as time to full oral feeding, need for feeding assistance with a feeding tube, inadequate food intake for age, or failure to thrive, for example, weight below the third percentile.[1,2,10] Although these outcomes are important, using assessments with evidence of reliability and validity helps to more accurately differentiate those with problematic feeding from those without. The only study of feeding in children with CHD that has used a valid and reliable assessment of feeding was a study by Hill et al of children with single-ventricle anatomy between the ages of 2 and 6 years.[3] This study used the Mealtime Behavior Questionnaire[11] to measure feeding dysfunction, and found that 50% of the children with single-ventricle anatomy had feeding dysfunction. This study provided critical information about the high prevalence of feeding problems in this specific population of children with univentricular hearts, but there are no studies on the broader population of infants and young children with CHD that have used a valid and reliable measure of oral feeding.

Recently, a new measure of symptoms of problematic feeding was developed called the Pediatric Eating Assessment Tool (PediEAT).[12–14] One significant difference between the Mealtime Behavior Questionnaire[11] and the PediEAT is that the PediEAT includes a set of items related to symptoms of aspiration, respiratory distress, and physiologic responses to oral feeding. These items are particularly important for infants and children with CHD who may be at risk for vocal fold palsy,[15] aspiration,[16] and physiologic distress during feeding.[17] The

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purpose of this study was to describe symptoms of problematic feeding, as measured by the PediEAT, in children with CHD compared to healthy children without medical conditions, taking into account child characteristics that may contribute to symptoms of problematic feeding.

Materials and methods

The original web-based studies under which these data were collected was approved by the Institutional Review Board at the University of North Carolina at Chapel Hill before commencement. This secondary analysis of de-identified data was deemed not human subjects research because it did not involve interaction or intervention with any individual and did not include identifiable private information, thus did not require Institutional Review Board approval. Primary caregivers, hereafter referred to as "parents," were invited to participate in an online survey about their child's eating. To be eligible to participate, parents had to be at least 18 years old, have access to the internet, self-identify as being literate in English, and have a child between the ages of 6 months and 7 years who were being offered solid food to eat by mouth. Solid foods were defined as anything other than liquids. Children who were exclusively fed by tube or parenteral nutrition were not included in this study.

The sample used for this analysis was selected from a larger sample of children with and without feeding problems that was collected over the course of multiple research studies. Parents were recruited from a variety of sites, including an announcement to faculty, staff, and students at the University of North Carolina at Chapel Hill, through web-based parent-support groups, Qualtrics panels, and through the North Carolina Children's Hospital primary care clinic, feeding clinic, and discharged patients from the neonatal ICU. In addition, parents were recruited from ResearchMatch, a national health volunteer registry supported by the United States National Institutes of Health as part of the Clinical Translational Science Award programme; Join the Conquest, a volunteer registry supported by the Clinical Translational Science Award at the University of North Carolina; and a registry of parents interested in participating in feeding-related research maintained by the author's research team. Parents in each of these studies were asked to complete an online survey that included questions about demographic characteristics of themselves, their child, and their family, questions about their child's medical and feeding history, and the PediEAT.

Sample

The target sample included children between the ages of 6 months and 7 years who had CHD and a control sample without CHD or other medical conditions. In order for children to be included in the sample without medical conditions, they had to be free of any of the following: speech-language delay, developmental delay, feeding problem diagnosed by a medical provider or described by parent as problematic, need for a feeding tube, epilepsy, CHD, autism spectrum disorder, metabolic disorder, cystic fibrosis, diabetes, intellectual disability, hearing impairment, vision impairment, eosinophilic esophagitis, celiac disease, sensory processing disorder, premature birth of <37 weeks gestation or genetic disorder. In addition, children were not included in the healthy, control sample if the parent reported that they were limited in any way from doing things other children of their age were capable of doing. All respondents had to have <10% missing data on the items of the PediEAT to be included.

Measures

PediEAT

The PediEAT is a 78-item parent-report assessment of symptoms of problematic feeding that is intended for children being offered solid foods between the ages of 6 months and 7 years. The PediEAT has four subscales, which were determined by exploratory factor analysis.[13] The Physiologic Symptoms subscale, with 27 items, measures symptoms of problematic feeding related to swallowing dysfunction, respiratory regulation, and gastrointestinal tract dysfunction. The Problematic Mealtime Behaviors subscale has 23 items and measures mealtime behaviours, such as refusing to eat, throwing food, taking a long time to eat, or insisting on food being presented in a certain way. The Selective/Restrictive Eating subscale, with 15 items, measures symptoms related to selectivity of the child during eating, such as willingness to eat different textures and temperatures of food. Finally, the Oral Processing subscale has 13 items and measures symptoms related to oral processing dysfunction, such as storing food in cheek, needing reminders to chew, preferring smooth foods that do not require chewing, or chewing on a bite for a long time. The specific items of the PediEAT are available in an earlier publication.[13]

The PediEAT was developed and content validated in collaboration with parents as well as professionals who care for children with feeding difficulty.[12] Psychometric testing of the PediEAT has demonstrated support for the reliability and validity of the tool. The PediEAT has acceptable internal consistency reliability for the full scale with Cronbach's $\alpha = 0.95$, and all subscales with Cronbach's $\alpha = 0.84–0.92$. It also has acceptable test/re-test reliability ($r = 0.87–0.95$, $p < 0.001$), construct validity with the mealtime behaviour questionnaire ($r = 0.46–0.77$, $p < 0.001$), and known-groups validity ($p < 0.001$).[13] Higher scores on the PediEAT indicate more symptoms of problematic feeding. Response options range from "Never" to "Always" along a six-point scale scored 0–5. Scores are calculated for each subscale, as well as for the full scale. With 27 items, scores range from 0 to 135 on the Physiologic Symptoms subscale. The possible range of scores on the 23-item Problematic Mealtime Behavior subscale is 0–115. Scores on the Selective/Restrictive Eating subscale range from 0 to 75 and on the Oral Processing subscale 0–65. The range of possible scores for the PediEAT total score is 0–390. Norm-reference values for scores on the PediEAT, based on a large sample of children within each of 11 age groups, are available to aid in interpretation of scores.[14]

Selection of covariates

To determine covariates to be included in the analysis, a literature search was conducted in PubMed using the search terms congenital heart AND disease OR defect AND feeding OR eating, with the following limits: English, full-text, humans, and ages birth to 12 years old. A total of 229 abstracts were reviewed, of which 28 were found to be relevant. These 28 full-text articles were reviewed for factors found to be significantly related to feeding, eating, or swallowing dysfunction in children with CHD in primary research studies. From this review, the following factors were determined to be possible covariates to be included in the analysis: duration of intubation,[2,10,18–20] types of CHD – single-ventricle versus double-ventricle, cyanotic versus acyanotic

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Table 1. Characteristics of parent, child, and family.

Variable of interest	Children without medical conditions, n	Children with CHD, n	Total sample, n (%)
Respondent's relationship to child (n = 1093)			
Mother	872	91	963 (88.1%)
Father	113	1	114 (10.4%)
Other primary caregiver	14	2	16 (1.5%)
Family type (n = 1092)			
Two parent	872	82	954 (87.4%)
One parent	100	8	108 (9.9%)
Other family type	27	3	30 (2.7%)
Family income (n = 1077)			
<$20,000	93	3	96 (8.9%)
$20,000–39,999	182	14	196 (18.2%)
$40,000–59,999	167	13	180 (16.7%)
$60,000–79,999	154	18	172 (16%)
$80,000–99,999	115	17	132 (12.3%)
>$100,000	273	28	301 (27.9%)
Parent education completed (n = 1093)			
High school or less	262	10	272 (24.9%)
Technical school/community college	151	12	163 (14.9%)
College/university or higher	586	72	658 (60.2%)
Child race (n = 1093)			
American Indian or Alaskan Native	2	0	2 (0.2%)
Asian	22	4	26 (2.4%)
Black or African American	56	1	57 (5.2%)
Hispanic or Latino	43	3	46 (4.2%)
Native Hawaiian or Pacific Islander	2	1	3 (0.3%)
White	702	76	778 (71.2%)
More than one race	172	9	181 (16.6%)

– or RACHS score,[2,10,20–22] gastroesophageal reflux,[10] genetic disorder,[19] early feeding disorder,[1] and history of cardiac surgery.[1]

Variables were selected from the data available for this analysis that most closely measured these factors. Duration of intubation, which may serve as a proxy for physiologic compromise, was measured by a question asking the parent to estimate the total duration of time their child had been intubated within the following categories: Never had a breathing tube, breathing tube <2 days, breathing tube 2 days to 1 week, breathing tube 1–2 weeks, and breathing tube >2 weeks. Type of CHD was collected in an open text box and categorized by the investigator as either no CHD, acyanotic heart disease – including atrial and ventricular septal defects, atrioventricular canal, pulmonary stenosis, patent ductus arteriosus, aortic stenosis, coarctation of the aorta, and arrhythmias – or cyanotic heart disease such as tetralogy of Fallot, transposition of the great arteries, hypoplastic left or right heart syndrome, pulmonary atresia, tricuspid atresia, and truncus arteriosus.[23] If the parent did not specify the type of CHD, this was considered missing data for this variable.

Gastroesophageal reflux was categorised as Yes or No based on the parent's response to the question: "Does your child have gastroesophageal reflux?" Genetic disorder was categorised as Yes or No based on parent's indication of presence of a diagnosed genetic disorder. Early feeding disorder was measured with two variables. Parents were asked to indicate whether their child had difficulty with breastfeeding or bottle-feeding as an infant and each of these variables was categorised as Yes or No. Finally, the parents were asked whether their child had cardiac surgery and

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Table 2. Age and sex characteristics of children in sample.

	Children without medical conditions		Children with CHD		
	Male	Female	Male	Female	Total
6 months–2 years	224	222	17	12	475 (43.4%)
2–4 years	137	144	21	17	319 (29.2%)
4–7 years	135	137	14	13	299 (27.4%)
Total, n (%)	496 (45.4%)	503 (46%)	52 (4.8%)	42 (3.8%)	1093

Table 3. Results of single covariate models for PediEAT total and subscale scores.

	Total PediEAT score	Physiologic symptoms	Problematic mealtime behaviours	Selective/restrictive eating	Oral processing
Breathing tube duration	0.004	0.001	0.07	0.03	0.22
Type of CHD	0.62	0.22	0.45	0.99	0.06
Gastroesophageal reflux	0.02	0.15	0.09	0.046	0.1
Genetic disorder	0.20	0.42	0.74	<0.001	0.29
Difficulty with bottle-feeding during infancy	<0.001	0.03	<0.001	<0.001	<0.001
Difficulty with breastfeeding during infancy	0.001	0.002	0.003	0.67	0.01
Cardiac surgery	0.50	0.58	0.048	0.13	0.02
Child's current age*	<0.001	<0.001	<0.001	<0.001	<0.001

Note. The data presented in the table are p-values; covariates with a significant effect on the total or subscale outcome, defined as a p-value of <0.05 (grey cells), were included in the multi-covariate model for the respective total or subscale outcome variable (Table 4). Descriptions of the variables used in the analysis are available in the text.
*Child age was categorised into three age categories: 6 months–2 years, 2–4 years, and 4–7 years.

this variable was categorised as Yes or No. For the purposes of this study, children were categorised by age into three age groups: 6 months–2 years, 2–4 years, and 4–7 years.

Statistical analyses

Data were analysed using the univariate general linear models function within IBM SPSS version 24. Analyses were conducted separately for the dependent variables of PediEAT total score, Physiologic Symptoms subscale score, Problematic Mealtime Behavior subscale score, Selective/Restrictive Eating subscale score, and Oral Processing subscale score. Differences between children with CHD and children without medical conditions were investigated for each of the dependent variables first with a single covariate in the model. Covariates that were found to be statistically significant, defined as a p-value <0.05, in the single covariate models were included in the final, multi-covariate model. PediEAT total score and the four subscale scores were then calculated for children with CHD compared to children without CHD or other medical conditions within each of the three age groups to show change in scores across age groups.

Results

Sample

The sample included 94 children with CHD and 999 children without CHD or other medical conditions. Characteristics of the parent respondent, their child, and family are presented in Table 1. Parent respondents were primarily from the United States (n = 1081), although there were also respondents from Australia (n = 2), Austria (n = 1), Canada (n = 1), the Netherlands (n = 1), New Zealand (n = 2), and the United Kingdom of Great Britain and Northern Ireland (n = 1). Data were missing on primary residence from three respondents. Within the United States, there were respondents from all 50 states and the District of Columbia. Distributions of the sample across child sex and age groups are presented in Table 2.

The sample of children with CHD was a heterogeneous sample in terms of type of CHD. Using the categorisation of cyanotic versus acyanotic heart disease described previously, there were 72 children in the sample with acyanotic heart disease and 18 with cyanotic heart disease. In the group of children with acyanotic heart disease, there were 38 with atrial or ventricular septal defects, one with atrioventricular canal, seven with patent ductus arteriosus or foramen ovale, three with pulmonary stenosis, two with aortic stenosis, one with bicuspid aortic valve, six with coarctation of the aorta, one with a cardiac arrhythmia disorder, six with murmurs of unknown clinical significance, and seven with other combined CHDs that were acyanotic in nature. Within the group of 18 children with cyanotic heart disease, there were nine with tetralogy of Fallot, five with hypoplastic left heart syndrome, one with pulmonary atresia, two with tricuspid atresia, and one with a complex CHD that was considered cyanotic in nature.

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Table 4. Results of multi-covariate models for PediEAT total and subscale scores.

Subscales	Parameters	Estimate	SE	*t*-value	p
PediEAT total score	Intercept	110.81	5.62	19.73	<0.001
(n = 1063)	CHD	45.46	5.44	8.36	<0.001*
	Breathing tube duration	3.13	1.96	1.60	0.11
	Gastroesophageal reflux	4.81	3.52	1.37	0.17
	Difficulty with bottle-feeding during infancy	15.07	3.51	4.29	<0.001*
	Difficulty with breastfeeding during infancy	5.61	2.12	2.65	0.01*
	Child's current age	−4.4	1.02	−4.31	<0.001*
Physiologic Symptoms	Intercept	26.07	1.63	16.01	<0.001
(n = 1068)	CHD	15.79	1.57	10.04	<0.001*
	Breathing tube duration	1.29	0.57	2.26	0.02*
	Difficulty with bottle-feeding during infancy	2.0	1.04	1.92	0.06
	Difficulty with breastfeeding during infancy	1.76	0.63	2.78	0.01*
	Child's current age	−2.49	0.31	−8.12	<0.001*
Problematic Mealtime	Intercept	34.39	2.85	12.05	<0.001
Behaviours	CHD	13.44	2.8	4.8	<0.001*
(n = 1068)	Cardiac surgery	4.25	3.4	1.25	0.21
	Difficulty with bottle-feeding during infancy	5.97	1.74	3.42	0.001*
	Difficulty with breastfeeding during infancy	3.13	1.05	2.98	0.003*
	Child's current age	4.16	0.51	8.16	<0.001*
Selective/Restrictive	Intercept	24.55	1.74	14.1	<0.001
Eating	CHD	6.09	1.71	3.55	<0.001*
(n = 1078)	Breathing tube duration	1.35	0.56	2.43	0.02*
	Genetic disorder	9.99	1.95	5.13	<0.001*
	Gastroesophageal Reflux	0.04	1.01	0.04	0.97
	Difficulty with bottle-feeding during infancy	4.6	1.04	4.41	<0.001*
	Child's current age	−2.84	0.30	−9.34	<0.001*
Oral Processing	Intercept	25.31	1.42	17.84	<0.001
(n = 1068)	CHD	9.51	1.39	6.84	<0.001*
	Difficulty with bottle-feeding during infancy	3.4	0.87	3.93	<0.001*
	Difficulty with breastfeeding during infancy	1.05	0.52	2.01	0.05
	Cardiac surgery	−3.05	1.69	−1.80	0.07
	Child's current age	−3.36	0.25	−13.26	<0.001*

*Notes.** indicates p<0.05.

Symptoms of problematic feeding and CHD status

The results of the individually tested covariates for each dependent variable are available in Table 3. The results of the final, multi-covariate models for each dependent variable are available in Table 4.

PediEAT total score

Children with CHD were found to have significantly higher PediEAT total scores compared to children without medical conditions of 110.52 versus 65.06; $t(1) = 8.36$, $p < 0.001$, taking into account breathing tube duration, gastroesophageal reflux,

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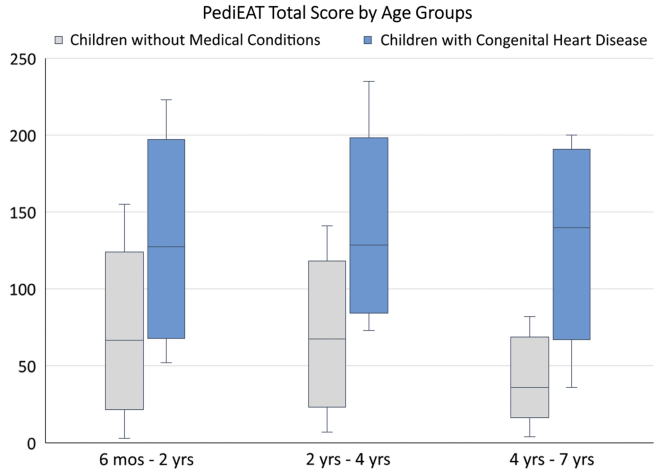

Figure 1. Children with CHD had significantly higher PediEAT total scores than children without CHD or other medical conditions within each age group ($p < 0.001$). The box plot indicates mean ± 1 SD. The whiskers indicate minimum and maximum values.

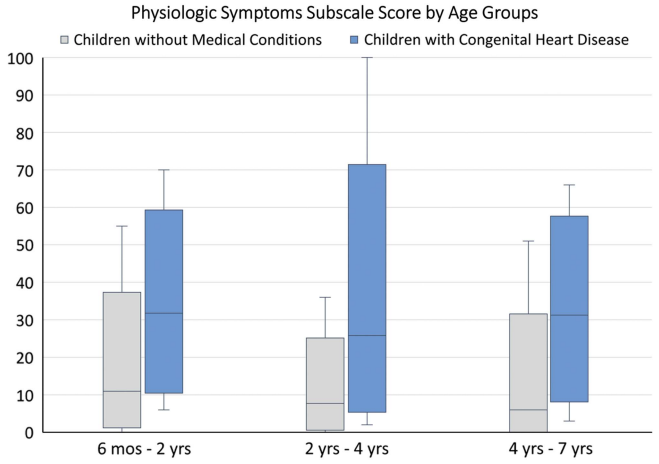

Figure 2. Children with CHD had significantly higher physiologic symptoms subscale scores than children without CHD or other medical conditions within each age group ($p < 0.001$). The box plot indicates mean ± 1 SD. The whiskers indicate minimum and maximum values.

difficulty with bottle-feeding as an infant, difficulty with breastfeeding as an infant, and child's current age. Difficulty bottle-feeding and breastfeeding during infancy was highly associated with PediEAT total score, when taking into account other covariates. Children who had difficulty with bottle-feeding during infancy had a PediEAT total score of 15.07 points higher than those without difficulty during infancy ($p < 0.001$). Children who had difficulty with breastfeeding during infancy had a PediEAT total score that was 5.61 points higher than those without breastfeeding difficulty ($p = 0.01$). Taking into account all other factors, PediEAT total score decreased by 4.4 points for each increase in age group category ($p < 0.001$). Comparisons of PediEAT total scores between children with CHD and those without medical conditions for each of the three age groups are available in Figure 1.

Physiologic Symptoms subscale score

Children with CHD had significantly higher scores on the physiologic symptoms subscale compared to children without medical conditions of 24.74 versus 8.95; $t(1) = 10.04$, $p < 0.001$, taking into account breathing tube duration, difficulty with bottle-feeding during infancy, difficulty with breastfeeding during infancy, and child's current age. Taking into account all other covariates, breathing tube duration ($p = 0.02$) and difficulty with breastfeeding during infancy ($p = 0.01$) were both associated with higher physiologic symptoms subscale scores. For each increase in category of breathing tube duration, physiologic symptoms subscale score increased by 1.29 points. Infants with a history of difficulty with breastfeeding during infancy had a higher physiologic symptoms subscale score by 1.76 points. Taking into account all other covariates, each increase in category of child age was associated with a decrease in physiologic symptoms subscale score by 2.49 points ($p < 0.001$). Comparison of physiologic symptoms subscale scores between children with CHD and those without medical conditions within each of the three age groups is available in Figure 2.

Problematic Mealtime Behaviour subscale score

Children with CHD had significantly higher scores on the problematic mealtime behaviour subscale of the PediEAT when compared to children without medical conditions of 39.28 versus 25.84; $t(1) = 4.8$, $p < 0.001$, taking into account history of cardiac surgery, difficulty with bottle-feeding during infancy, difficulty with breastfeeding during infancy, and child's current age. Taking into account other covariates, history of difficulty with bottle-feeding during infancy ($p = 0.001$) and difficulty with breastfeeding during infancy ($p = 0.003$) were both associated with higher scores on the problematic mealtime behaviour subscale. Children with a history of difficulty with bottle-feeding during infancy had a problematic mealtime behaviour subscale score that was 5.97 points higher than children without a history of difficulty with bottle-feeding. Children with a history of difficulty with breastfeeding had a problematic mealtime behaviour subscale score that was 3.13 points higher than children without breastfeeding difficulty. Finally, child's current age was significantly related to problematic mealtime behaviour subscale score, taking into account all other covariates ($p < 0.001$). Unlike the PediEAT total score and all other subscale scores where increasing category of child age was associated with a decrease in PediEAT score, each increase in category of child age was associated with a 4.16 point increase in problematic mealtime behaviour subscale score. Problematic mealtime behaviour subscale scores between children with CHD and those without medical conditions within each of the three age groups are available in Figure 3.

Selective/Restrictive Eating subscale score

Children with CHD had higher scores on the selective/restrictive eating subscale score compared to children without medical conditions of 23.16 versus 17.07; $t(1) = 3.55$, $p < 0.001$, taking into account breathing tube duration, genetic disorder, gastroesophageal reflux, difficulty with bottle-feeding during infancy, and child's current age. Taking into account all other covariates, each category increase in breathing tube duration was associated with a 1.35-point increase in selective/restrictive eating subscale score ($p = 0.02$). Children with a diagnosed genetic disorder had a 9.99-point increase in selective/restrictive eating subscale score, taking into account all other covariates ($p < 0.001$). Difficulty with bottle-feeding during infancy was associated with a 4.6-point increase in selective/restrictive eating subscale score, taking into account other covariates ($p < 0.001$). Taking into account all other covariates, each increase in category of child age was associated

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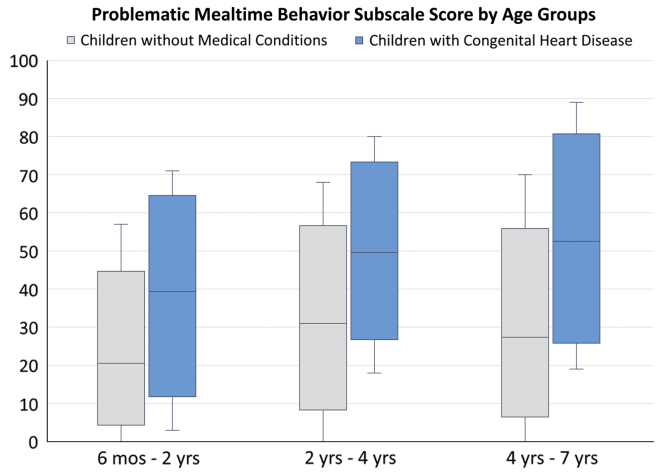

Figure 3. Children with CHD had significantly higher problematic mealtime behaviour subscale scores than children without CHD or other medical conditions within each age group ($p < 0.001$). The box plot indicates mean ±1 SD. The whiskers indicate minimum and maximum values.

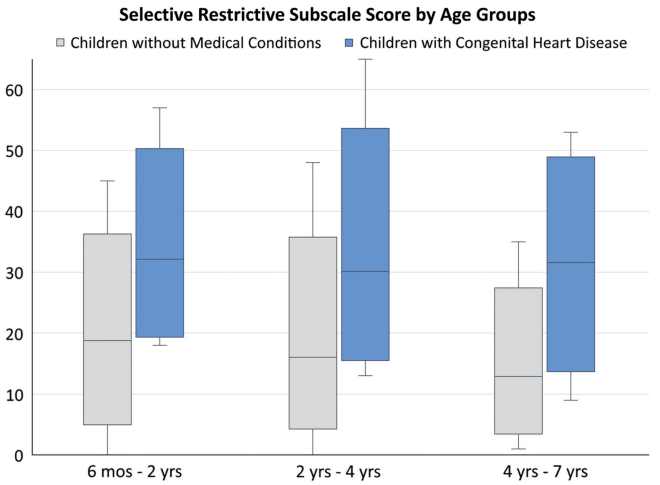

Figure 4. Children with CHD had significantly higher selective restrictive subscale scores than children without CHD or other medical conditions within each age group ($p < 0.001$). The box plot indicates mean ±1 SD. The whiskers indicate minimum and maximum values.

with a 2.84 decrease in selective/restrictive eating subscale score ($p < 0.001$). Figure 4 presents the comparison of selective/restrictive eating subscale scores between children with CHD and those without medical conditions within each of the three age groups.

Oral Processing subscale score

Children with CHD had more symptoms of oral processing dysfunction when compared to children without medical conditions of 22.96 versus 13.45; $t(1) = 6.84$, $p < 0.001$, taking into account difficulty with bottle-feeding during infancy, difficulty with breastfeeding during infancy, history of cardiac surgery, and child's current age. Difficulty with bottle-feeding during infancy was associated with a 3.4-point increase in oral processing subscale score ($p < 0.001$), taking into account other covariates. Each increase in child age category was associated with a 3.36-point decrease in oral processing subscale score ($p < 0.001$), taking into account all other covariates. Figure 5 presents the oral processing subscale score comparisons between children with CHD and those with no medical conditions within each of the three age groups.

Discussion

This manuscript presents the largest study to-date comparing symptoms of problematic feeding between children with CHD and healthy children, using a valid and reliable measure of oral feeding. The results of this study revealed that children with CHD had more symptoms of problematic feeding than children without CHD or other medical conditions for the PediEAT total score and all subscales of the PediEAT, taking into account variables that have been found to be associated with problematic feeding in this group of children. Although it would be expected that children with CHD would have higher scores on the physiologic symptoms subscale, which measures symptoms common in children with CHD, such as respiratory distress during feeding, swallowing dysfunction, and gastrointestinal tract dysfunction, this study revealed that children with CHD experience increased symptoms of problematic feeding across all domains. Children with CHD also had more problematic mealtime behaviors, more selective/restrictive eating behaviours, and more oral processing dysfunction than their healthy peers.

Interestingly, in this analysis, type of CHD – cyanotic versus acyanotic – was not found to be a significant covariate in any of the models. This suggests that all children with CHD, regardless of type, are at risk for problematic feeding. This was true for a group of children with a heterogeneous mix of CHDs, some of which were not haemodynamically significant. Similarly, a history of cardiac surgery was not found to be a significant covariate in any of the models. Certain surgical procedures, for example, those involving the aortic arch, have been associated with increased risk for vocal cord paralysis/paresis, dysphagia, and aspiration.[15,18,24,25] The current study was limited in that cardiac surgery was categorised as "Yes" if the child had cardiac surgery or "No" if the child had never had cardiac surgery. A larger study with more specific information about surgical procedures is needed to compare feeding outcomes by surgical procedure type.

Child's current age was the only covariate that was found to be significantly related to all of the outcome variables such as PediEAT total score and all subscale scores, taking into account CHD status and all other covariates. PediEAT total score, physiologic symptoms subscale score, selective/restrictive eating subscale score, and oral processing subscale score all decreased with increasing child age, whereas problematic mealtime behaviour subscale score increased with age. This finding is consistent with previously published data that showed increasing problematic mealtime behaviour scores in healthy, typically developing children until age 3, and then decreasing thereafter; whereas other subscale scores generally decreased with increasing child age.[14] The data presented in this study suggest that physiologic symptoms, symptoms of selective and restrictive eating behaviours, and oral processing dysfunction improve over time for all children, but children with CHD continue to have more symptoms of problematic eating than their healthy peers.

Another interesting finding from this study was that a parent-reported history of either difficulty with breastfeeding or bottle-feeding was found to be significantly associated with PediEAT total score and all four subscale scores, taking into account CHD status and all other covariates. This suggests that, regardless of CHD status, children who struggle with feeding early in life are more

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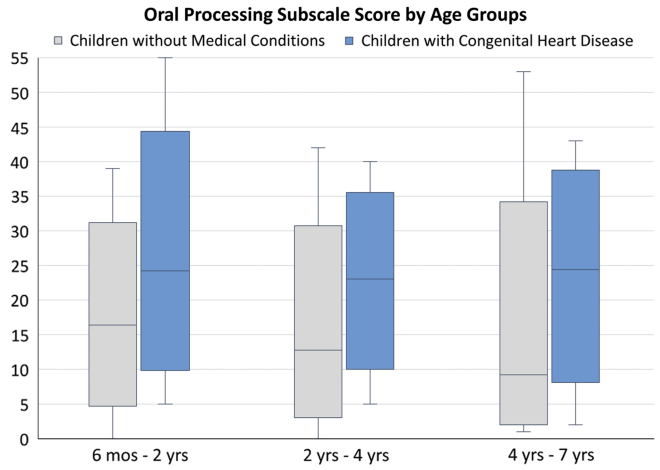

Figure 5. Children with CHD had significantly higher oral processing subscale scores than children without CHD or other medical conditions within each age group ($p < 0.001$). The box plot indicates mean ±1 SD. The whiskers indicate minimum and maximum values.

likely to struggle with feeding in childhood. This is consistent with other studies that have found that while diagnosis of a feeding problem does not occur, on average, until 2.4 years,[26] parents of children who are later diagnosed with feeding problems often report that these problems began in early infancy, sometimes shortly after birth.[27] Although our study was cross-sectional and limited by the way of feeding problems were assessed during infancy, that is parents were asked to report "yes" or "no" the child experienced difficulties with breast or bottle feeding, these findings provide important support for further longitudinal investigations describing the evolution of problematic feeding behaviours. Across all diagnostic categories, it is critical to understand which children with feeding difficulties during infancy improve and which do not, so that we can tailor care and provide early intervention, where needed, to improve long-term feeding outcomes.

Breathing tube duration was found to be significantly associated with the subscales scores for physiologic symptoms and selective/restrictive eating, taking into account CHD status and other factors. There is some current literature that has found that longer duration of endotracheal intubation is associated with swallowing difficulties in children[28] and adults.[29] Since the physiologic symptoms subscale measures behaviours associated with swallowing dysfunction and respiratory regulation, this finding was consistent with the literature. The finding that the selective/restrictive eating subscale score was significantly associated with duration of intubation is a particularly interesting finding because this suggests that children with a longer history of intubation may be at risk for sensory disturbances that affect their eating. Although there is certainly anecdotal evidence and theoretical speculation that the presence of an endotracheal tube in the mouth or nose for any extended duration of time may either directly affect the sensory nerves along the tract of the tube or may result in changes in the brain's interpretation of sensations along the tract of the tube, no other studies have documented this relationship between endotracheal intubation and selective/restrictive eating. Further exploration of this phenomenon using more accurate measurements of endotracheal intubation time and exploration of underlying mechanisms for this relationship are warranted.

Finally, genetic disorder was found to be significantly associated with selective/restrictive eating subscale score, taking into account CHD status and all other covariates. There is some evidence in the literature that children with genetic disorders are at risk for alterations in sensory processing that result in sensory-averting or sensory-seeking behaviours.[30,31] These types of sensory-related behaviours have also been linked to selective eating behaviours in children with autism spectrum disorder.[32]

Study strengths and limitations

The primary strengths of this study were that the sample size was large and feeding was measured using the PediEAT, an assessment tool with evidence of validity and reliability. The primary limitation of this study was that it was a web-based survey that was reliant on parent-report. Although this type of study allows for a large sample size across broad geographic locations, future explorations of this phenomenon would be strengthened by validation by medical records, specifically for type of CHD, duration of endotracheal intubation, and cardiac surgical procedures. Although the overall sample size was relatively large, the sample of children with CHD was heterogeneous and there were not enough children to be able to run analyses by number of functional ventricles. It is likely that certain types of CHD are associated with more problematic feeding symptoms and this should be explored in future studies. In addition, the respondents were primarily white, well-educated mothers within two-parent families; this may be a result of the web-based nature of the study. Future studies with clinical samples should aim to include a more ethnically and socioeconomically diverse sample. Finally, the parent report of difficulty with bottle-feeding and breastfeeding during infancy was reported as yes or no. Given that these factors were found to be highly related to the total score and many of the subscale scores, prospective, longitudinal studies are needed, using valid and reliable measures of infant feeding such as the Neonatal Eating Assessment Tool,[33–35] to explore the relationships between feeding in early infancy and later childhood.

Conclusion and future directions

This study found that children with CHD experience more symptoms of problematic feeding than their healthy peers across all age groups and all domains of oral feeding. These findings highlight the need for early and frequent assessment of feeding in the clinical care of all children with CHD, regardless of age or physiologic compromise. Use of standardised assessment tools, such as the PediEAT, may help to identify children who are struggling with feeding and facilitate timely referral to feeding specialty care in order to optimise long-term outcomes.

Much research is needed to improve our understanding of the unique difficulties that children with CHD face with regards to oral feeding in order to develop interventions to optimise their growth, development, and oral feeding abilities. This study identified other factors that were associated with increased symptoms of problematic feeding taking into account CHD status, such as difficulty with breast- or bottle-feeding during infancy, breathing tube duration, and genetic disorder. Children with CHD, in addition to these other compounding factors, particularly may be at high risk for problematic feeding. Prospective, longitudinal exploration of the relationships studied in this cross-sectional data is needed to determine factors that place particularly a child at high risk for problematic feeding. This would allow for improved risk assessment, earlier referral to

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feeding specialty care, and improved anticipatory guidance to parents.

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Conflicts of Interest. None.

Ethical Standard. The author asserts that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation (US Department of Health & Human Services, Office for Human Research Protections) and with the Helsinki Declaration of 1975, as revised in 2008. The original studies under which data were collected were approved by the Institutional Committee at the University of North Carolina at Chapel Hill. This secondary analysis of de-identified data was deemed not human subjects research because it did not involve interaction or intervention with any individual and did not include identifiable private information, thus did not require Institutional Review Board approval.

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