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Feeding dysfunction in single ventricle patients with feeding disorder

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Abstract

Purpose—To determine whether caregivers of children with single ventricle heart defects identified as having feeding disorder will report more frequent feeding dysfunction, or maladaptive mealtime behavior and/or interactions, when compared to reference populations.

Methods—As part of routine evaluation, parents of children evaluated at the Feeding, Swallowing, and Nutrition Center at the Children's Hospital of Wisconsin completed previously validated questionnaires to assess feeding dysfunction and parental stress. Parental responses for single ventricle patients were compared to all other children evaluated with a feeding disorder.

Results—Questionnaires were completed in 8 patients with single ventricle heart defects. The mean age was 36 ± 23 months, with 5 females (63%). Mean weight-for-age Z score was -1.4 ± 0.9. Compared to non-cardiac feeding clinic children, there was more reported child resistance to eating (83 ± 15% versus 44 ± 2%; p = 0.05). Single ventricle parents were more likely to report distress (50 ± 18% versus 21 ± 2%; p = 0.04) and a difficult child (63 ± 17% versus 31 ± 2%; p = 0.05). There was also more defensive responding among parents of single ventricle children (63 ± 17% versus 29 ± 2%; p = 0.04).

Conclusion—Single ventricle patients evaluated for disordered feeding more frequently showed resistance to eating and parental distress than non-cardiac feeding clinic patients. Parents of these children underestimated the degree of feeding difficulty by defensive responding and had more parental distress. These findings suggest that feeding dysfunction can contribute to longer term feeding and growth problems in single ventricle patients with feeding disorder.

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Keywords

Single ventricle; feeding; nutrition; growth

Introduction

Children with congenital heart disease face significant risk of growth failure and feeding difficulties (1,2). Furthermore, those with single ventricle physiology are at particular risk of associated feeding complications such as an increased risk of necrotizing enterocolitis, poor growth and feeding disorders(2,3). These patients require staged palliation, often with an initial surgery in the first few days of life with prolonged disruption of oral feeding due to preoperative concern for NEC and prolonged critical illness during the post-operative recovery. Frequently patients with hypoplastic left heart syndrome (HLHS) require placement of a gastrostomy (G) tube in the post-operative period for feeding disorder(3,4). Many single ventricle patients show catch up growth after bidirectional cavopulmonary anastomosis(5). However, inadequate intake requiring nasogastric (NG) or G tube supplementation persists in 18% of patients in the period between bidirectional cavopulmonary anastomosis and Fontan and 5% of patients after Fontan(6). This persistence of feeding difficulties is not well understood. Feeding difficulties are associated with interstage mortality and earlier bidirectional cavopulmonary anastomosis(4), and low weight for age z-score at the time of cavopulmonary anastomosis surgery is also associated with longer hospital stay post-operatively(7). These factors are likely a cause of significant parental anxiety in regards to feeding and nutritional status. Over time, parental stress can lead to dysfunctional feeding strategies, which could explain the persistence of feeding problems in some cases. To date, no study has quantified the psychosocial stress and evaluated feeding dysfunction, or maladaptive mealtime behaviors or interactions, in single ventricle families. We sought to assess the psychosocial stress in both the parents and patients using previously validated questionnaires. The *Parenting Stress Index* (PSI) is a questionnaire that has been used to assess the stress present in a parent-child interaction(8). The *About Your Child's Eating* (AYCE) questionnaire and the *Mealtime Behavior Questionnaire* (MBQ) have been validated to measure the child-parent interaction as it specifically relates to feeding(9,10). We assessed the hypothesis that in patients with single ventricle physiology and feeding disorder, feeding dysfunction is more common than a reference population also with feeding disorder.

Methods

The study protocol was reviewed and approved by the institutional review board of the Children's Hospital of Wisconsin and informed consent was obtained. All patients presenting to the Feeding, Swallowing, and Nutrition Center at the Children's Hospital of Wisconsin were administered the *Mealtime Behavior Questionnaire*, *About Your Child's Eating*, and/or the *Parenting Stress Index*. Those with single ventricle physiology were isolated from the database and analyzed. These patients were then compared to previously published normal controls and to non-cardiac patients presenting to the same clinic. Data are

expressed as means ± standard deviation and comparisons between groups were performed using chi-squared testing.

Results

From 2003-2010, 8 patients with single ventricle physiology were evaluated in the Feeding, Swallowing, and Nutrition Center at the Children's Hospital of Wisconsin and completed appropriate questionnaires. Cardiac anatomy consisted of: 4 patients with HLHS, 2 patients with pulmonary atresia with an intact ventricular septum, 1 patient with unbalanced atrioventricular septal defect and 1 patient with tricuspid atresia with interrupted aortic arch. At the time of questionnaire administration the mean age was 36 ± 23 months with 5 females (63%). Six patients were status post Fontan while 2 were status post cavopulmonary anastomosis without Fontan completion. The mean weight-for-age Z score was -1.4 ± 0.9. G tubes were present in 7 patients (89%) for supplementation of oral feeds. All single ventricle patients had choking, gagging or vomiting. These patients were compared to patients presenting to the feeding clinic feeding disorder related to a variety of underlying problems such as extreme prematurity, cerebral palsy and solid organ transplantation. The mean age was 40 ± 31 months. Results of comparison with normal controls can be seen in Table 1 and with other feeding clinic patients in Table 2. Single ventricle patients had significantly more resistance to eating than the normal controls (83 vs. 1.3%, p value < 0.0001) and the non-cardiac feeding disorder group (44%, p value = 0.05). Parents of single ventricle patients more frequently had distress and rated their child as difficult more often than non-cardiac feeding disorder patients. There was also significantly more defensive responding in the single ventricle group than the feeding disorder control group (63 vs. 29%; p value = 0.04).

Discussion

Of all cardiac patients, those with single ventricle physiology have the most feeding difficulties and are slowest to reach enteral feeding goals(11,12). Investigations exclusively of the single ventricle population have shown that factors such as timing of enteral feeds, duration of ventilation, total hospital course and readmission rates were not associated with poor growth (13). Many strategies are used to overcome the poor feeding and growth encountered in single ventricle patients, including supplementation of volume with tube feedings, whether by G tube or NG tube, and increases in caloric density. NG or G tube supplementation of feedings is reported in 25-75% of patients prior to bidirectional Glenn(6,13). In spite of these strategies, there continues to be growth problems. At the time of cavopulmonary anastamosis 50% of patients were severely underweight (14) and 89% failed to meet CDC standards for growth(7).

Home monitoring strategies are used at our institution and many others, which includes measurement of daily weight, with guidelines to report a loss of >30g in 24 hours, failure to gain at least 20g in 3 days or daily intake of <100ml/kg/day. This has improved interstage survival, with those in breach of guidelines undergoing earlier cavopulmonary anastamosis(4). The majority of violations of these guidelines were isolated to feeding or growth problems. The use of this aggressive nutritional plan has resulted in normal growth for interstage patients with improved mortality (15). However, this may place a greater

stress on families at mealtime. Parents realize that poor growth and intake may equate to worse outcomes or at the very least, further medical evaluation including possible inpatient monitoring.

After cavopulmonary anastomosis surgery, there is significant catch up growth in most single ventricle patients but inadequate intake requiring NG or G tube supplementation persists in 18% of patients in the pre-Fontan period and 5% of patients after Fontan(6). This raises concern that environmental, and more specifically psychosocial, factors could play a significant role in these patients. We proposed that over time feeding problems could be replaced by dysfunctional feeding strategies that create a cycle of poor feeding and further stress and feeding dysfunction. These data indicate that single ventricle patients presenting to the feeding clinic are more resistant to feeding and therefore, there is more parental distress than in non-cardiac patients with similar feeding disorder. Single ventricle parents also significantly underestimate the problems with defensive responding, or trying to normalize their child's behavior.

There are limitations to this data, in particular the small sample size and patient selection, in that all the patients were presenting to the Feeding, Swallowing, and Nutrition Center. Future study may include administration of the questionnaires to a large cohort of single ventricle patients to determine the true incidence of feeding dysfunction in this group and risk factors for development of feeding dysfunction.

Conclusion

Single ventricle patients with feeding disorder show more resistance to feeding than non-cardiac patients with feeding disorder. Single ventricle caregivers normalize their child's behavior with defensive responding. Early assessment for feeding dysfunction is warranted in single ventricle patients with feeding disorder.

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Table 1

Comparison of single ventricle patients with normal controls.

	Single ventricle patients	Normal controls	
Feature	**Percent Positive**	**Percent positive**	**p value**
MBQ	N=7	N=355	
Distraction/Avoidance	29	6.1	0.02
Food manipulation	43	5.0	<0.0001
Aggression	14	4.1	0.2
Choking, gagging, vomiting	100	7.6	<0.0001
AYCE	N=6	N=384	
Child resistance to eating	83	1.3	<0.0001
Positive mealtime environment	33	4.4	0.0005
Parent aversion to mealtime	67	1.0	<0.0001

MBQ – Mealtime Behavior Questionnaire, AYCE – About your Child's Eating, PSI – Parental Stress Index

Table 2

Comparison of single ventricle patients with non-cardiac patients presenting to the Feeding, Swallowing and Nutrition clinic.

	Single ventricle patients	Other feeding disorder patients	
Feature	**Percent Positive**	**Percent positive**	**p value**
MBQ	N=7	N=665	
Distraction/Avoidance	29	23	0.73
Food manipulation	43	51	0.68
Aggression	14	30	0.36
Choking, gagging, vomiting	100	71	0.09
AYCE	N=6	N=745	
Child resistance to eating	83	44	0.05
Positive mealtime environment	33	50	0.42
Parent aversion to mealtime	67	37	0.13
PSI	N=8	N=669	
Total stress	38	29	0.60
Parental distress	50	21	0.04
Dysfunctional interaction	50	25	0.10
Difficult child	63	31	0.05
Defensive responding	63	29	0.04

MBQ – Mealtime Behavior Questionnaire, AYCE – About your Child's Eating, PSI – Parental Stress Index