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Short Communication

Home-Based Appetite-Guided Weaning of Enteral Nutrition of Infants with Congenital Heart Disease: A Preliminary Clinical Observation

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Abstract

Infants with a critical congenital heart defect are at high-risk for feeding difficulties, often necessitating feeding tube placement. Enteral nutrition (EN) support is initiated to meet nutritional requirements and promote growth pre- and post-operatively. Tube-fed infants with congenital heart disease (CHD) who achieve stable health status post-operatively are at risk of becoming feeding tube dependent (FTD). We report a clinical observation for infants with CHD based on survey results from *Growing Independent Eaters (GIE)*, a company that utilizes a home-based, appetite-guided method to transition infants and children from FTD to oral eating. GIE surveyed families who participated in a GIE-led wean from June 2018 to December 2018 for program evaluation, quality improvement, and outcomes measurement. The cohort of 14 infants (ages 0-12 months) was categorized as: CHD only, CHD plus other

diagnoses, and no CHD plus other diagnoses. Median wean duration for infants with CHD only (Mdn = 18.0 days, IQR = 9.5-38.5) was similar to infants with CHD plus other diagnoses (Mdn = 25.0 days) but shorter than infants with medical conditions other than CHD (Mdn = 63.0 days, IQR = 28.0-90.0). Mean loss of body weight during the wean was similar for all groups. These observations highlight that the GIE method of enteral weaning provides FTD infants with and without CHD the necessary support to successfully wean off EN, albeit faster for those infants with a diagnosis of CHD. Further studies are now required using a larger cohort of infants to support these promising preliminary findings.

Keywords
Home enteral nutrition support; pediatric feeding tube-weaning; feeding tube dependency

1. Introduction

Infants with congenital heart disease (CHD) may experience tachypnea, increased metabolic demand, and poor feeding endurance, resulting in growth faltering from inadequate oral intake of energy and nutrients [1, 2]. Feeding tubes are frequently placed to meet the infant's nutritional requirements and maintain adequate growth during this critical time before and after cardiac surgery [1-5].

While enteral nutrition (EN) is beneficial, it is a medical intervention with significant side effects including oral aversion, psychological stress, and medical complications [3-6]. While feeding tube dependency (FTD) is well described in the literature, once the infant is medically stable, there is no best practice for enteral weaning [3, 6]. Tube-fed infants who remain on EN beyond medical necessity may develop FTD, which is the inability to transition to an oral diet despite stable health status and the ability to swallow safely [3-7].

Given the complexity of enteral tube weaning, medical personnel are often hesitant to recommend enteral weaning if the infant remains small by weight, lacks oral skills, or does not demonstrate oral interest [8]. Most interventions utilize a multidisciplinary, behavioral, and/or hunger provocation approach to enteral weaning [9, 10]. Variability exists within weaning programs worldwide with regard to therapeutic intervention, as well as in treatment setting (inpatient, outpatient, home-based, or telehealth) [9, 10]. Enteral wean programs also vary by rate of tube feeding reduction (predetermined timeline vs. child-led) [11-19]. This preliminary study conducted through Growing Independent Eaters (GIE), a privately operated program conducted in the home setting, utilizes a child-led appetite-based approach to enteral weaning and has demonstrated success overcoming FTD [16]. The GIE program offers families guidance and support from a virtual interdisciplinary team, comprised of a feeding therapist, parent coach, registered dietitian, and mental health social worker. This article discusses survey results for infants with and without CHD who used the GIE method of enteral weaning. The aim of this study was to examine the effect of CHD diagnosis on enteral wean duration and postwean growth velocity compared with other medical diagnoses in infants who followed the GIE method of enteral weaning. A secondary aim was to gather qualitative comments from parents/caregivers on their perception of quality-of-life (QOL) postwean.

2. Materials and Methods

2.1 GIE Method

As previously reported in the literature [16], the GIE method of enteral weaning starts with an intake process to screen for parent and child wean readiness. An electronically submitted intake form details the child's medical, developmental, growth, feeding, and nutrition history, as well as parental concerns related to feeding, growth, and development. The GIE interdisciplinary team reviews all intake forms for wean eligibility. To be wean eligible, the child must be medically stable (defined as no acute change in the medical condition or treatment [20]) as determined by the child's local medical team (e.g., primary care physician and/or specialist chosen by the family) and reported by the parents/caregivers, have demonstrated weight gain for minimum of 4 weeks on their current home enteral regimen, and have evidence of a safe swallow as assessed by the child's local medical team via clinical swallow examination or video fluoroscopic swallow examination.

The GIE interdisciplinary team then meets with parents/caregivers virtually via Zoom for up to one hour on two separate occasions (once with the parent coach and once with the feeding therapist or registered dietitian) to obtain consistent information about mealtime dynamics, feeding strategies, growth status, medical updates, and family stressors. During this interview process, details about the infant's home enteral feeding routine are reviewed. Infants receiving cyclic drip feeds into the stomach are transitioned to a bolus feeding schedule to mimic natural feeding rhythms prior to wean initiation. The interdisciplinary team works in collaboration with the infant's local medical team to monitor health during the wean process. Parents/caregivers provide the GIE team with a minimum of a once-a-week update based on their own observations and interactions with their local medical team. The frequency of these interactions are based on the recommendation of the child's local team and individualized to the medical needs of the child. Members of the GIE team communicate via email, phone call, and/or Zoom. The frequency and preference for route of communication are determined by the parent/caregiver.

Once parents/caregivers enroll in the program, they meet with the mental health social worker to discuss past and current stressors and identify coping strategies to mediate stress throughout the wean. Lastly, parents/caregivers are provided with an individualized wean plan for reducing EN over a series of steps (Table 1). All children follow the same series of steps, regardless of their daily quantity of oral intake prior to wean initiation. The timing for each tube feed reduction is child-led based on qualitative and quantitative progress plateaus, rather than a specific time frame [16]. This child-led approach reduces tube feeds in a step-wise manner, guided by the infant's readiness cues (e.g., engagement with food and mealtime comfort/trust) and hunger cues instead of a predetermined wean timeline [16]. While other child-led wean approaches are available, the GIE approach differs by making smaller reductions over a longer period of time compared to other child-led wean models that reduce large volumes with a shorter timeline [9, 10, 12-15, 19].

Table 1 Growing Independent Eaters Wean Steps.

	Step 1	**Step 2**	**Step 3**	**Step 4**
Tube feeding reduction	Tube fed volume reduced by 25-35%	Tube fed volume reduced by another 25-35%	Tube fed volume reduced by another 25-35%	Tube feeds discontinued
Oral diet	● Oral food/bottles offered every 2-3 hours throughout the day ● Additional night time bottle offers for young infants ● Offer at night for children only if they naturally wake	● Oral food/bottles offered every 2-3 hours throughout the day ● Additional night time bottle offers for young infants ● Offer at night for children only if they naturally wake	● Oral food/bottles offered every 2-3 hours throughout the day ● Additional night time bottle offers for young infants ● Offer at night for children only if they naturally wake	Maintain structured eating routine
Qualitative changes	Measures of qualitative progress: ● Decreasing feeding aversion/refusal ● Increasing comfort and attention span around food/bottles	Measures of qualitative progress: ● Decreasing feeding aversion/refusal ● Increasing comfort and attention span around food/bottles ● Increasing qualitative engagement (touching, licking, chomping) ● Bottle, cup, or food curiosity and exploration	Measures of qualitative progress: ● Resolution of feeding aversion/refusal ● Tolerance of feeding environment ● Ongoing bottle, cup, or food curiosity and exploration ● Increasing feeding coordination	Measures of qualitative progress: ● Positive mealtime experiences based on comfort and trust ● Sustained engagement with food/bottles ● Increasing feeding coordination and skill
Quantitative changes	Measure of quantitative progress: ● Hunger cues are just starting to wake up which may or may not translate into oral eating	Measure of quantitative progress: ● Hunger cues become stronger and usually translates into some oral eating	Measure of quantitative progress: ● Hunger cues become stronger and promote increasing oral volumes	Measure of quantitative progress: ● Intrinsically eating to appetite
Wean plateau	When the child reaches a wean plateau, it is time to	When the child reaches a wean plateau, it is time to	When the child reaches a wean plateau, it is time to	Wean is complete and child starts to consume sufficient

move to the next step. A wean plateau is reached when: ● Qualitative progress has stabilized ● No additional quantitative progress as hunger cues do not translate into more oral volume	move to the next step. A wean plateau is reached when: ● Qualitative progress has stabilized ● No additional quantitative progress as hunger cues do not translate into more oral volume	move to the next step. A wean plateau is reached when: ● Qualitative progress has stabilized ● Oral volumes are measurable, but inconsistent	energy/nutrients to promote upward growth trend.

2.2 Survey Participants and Procedure

A retrospective review of GIE client records identified 76 families who participated in a GIE program for enteral weaning between June 2018 and December 2018. In March 2020, each family was given 3 weeks to electronically complete and return the survey [16]. Survey data gathered included participant characteristics, feeding practices, quantitative measures to assess wean duration and weight changes, and qualitative comments from parents/caregivers describing changes in perceptions of QOL postwean. This study reports on a subset of previously published data.

2.3 Ethics Statement

This study was reviewed by the Washington State University Human Research Protection Program (HRPP), which determined that the protocol satisfied the criteria for exempt research, protocol 19149-001. There were no identifiers to link the survey to the participant. Informed consent was obtained electronically from the families of all participants.

2.4 Data Analysis

The preliminary data represented in this article is based on observations made from survey results, specifically for infants with CHD post-surgical repair. Statistical analyses were performed with the software package SPSS (version 22, SPSS Inc, Chicago, IL). The duration of tube wean is presented as median (IQR) and the percent loss of body weight is presented as mean (SD). Mann-Whitney *U* tests were used to detect differences between infants categorized by diagnosis (CHD vs. no CHD). An uncorrected α-criterion of 0.05 was used for all tests.

3. Results

Survey data was received from 31 families for a response rate of 40.8%. These 31 surveys included information from 16 families with infants (ages 0-12 months) and 15 families with children (ages 1-5 years). Two infants were excluded for incomplete data collection and all 15 children were excluded due to limited sample size (n = 3) with CHD. The data received from 14 families with infants represents the data discussed in this article.

Clinical characteristics of the study participants are described in Table 2. Prior to starting the wean, all infants were on a bolus feeding schedule and were reliant on EN to meet 50-100% of estimated energy needs via nasogastric tube or surgically placed gastrostomy tube.

Table 2 Demographic and clinical characteristics of study participants.

Participant demographics	Results
Chronological age	
0-6 months	5/14 (35.7%)
6-12 months	9/14 (64.3%)
Sex	
Male	7/14 (50.0%)
Female	7/14 (50.0%)
Gestation at birth	
Term (≥37 weeks' gestation)	9/14 (64.3%)
Prematurity (<37 weeks' gestation)	5/14 (35.7%)
23-25 weeks	1/5 (20.0%)
26-28 weeks	0/5 (0%)
29-31 weeks	0/5 (0%)
32-34 weeks	1/5 (20.0%)
35-36 weeks	3/5 (60.0%)
Classification of infants with CHD	
CHD as sole diagnosis	6/14 (42.9%)
CHD plus other diagnoses*	2/14 (14.3%)
No CHD plus other diagnoses*	6/14 (42.9%)
Type of feeding tube	
Nasogastric tube	12/14 (85.7%)
Gastrostomy tube	2/14 (14.3%)
Percentage of energy intake provided by TF prewean	
Exclusive TF (75%-100%)	13/14 (92.9%)
Partial TF (50%-75%)	1/14 (7.1%)
Prewean oral intake	
Partial oral nutrition (50-99% oral)	8/14 (57.1%)
No oral nutrition (0% oral)	6/14 (42.9%)

*Other diagnoses included gastrointestinal disorders, pulmonary/respiratory disorders, pediatric feeding disorder, and genetic disorders

Abbreviation: CHD, congenital heart disease; TF, tube feeding.

3.1 Wean Duration and Success

GIE defines "wean duration" as the interval between the first day of tube feeding reduction until tube feeds are discontinued. In this cohort of 14 infants, all 14 fully weaned off enteral support, with a median wean duration of 28.0 days (IQR = 18.0-46.0).

Information about medical diagnosis was collected from 14 participants. As illustrated in Figure 1, the 6/14 infants with CHD as the sole diagnosis had a similar wean duration to the 2/14 infants

with CHD plus other diagnoses of genetic disorder, pulmonary/respiratory disorder, and/or gastrointestinal disorder (Mdn = 18.0 days, IQR = 9.5-38.5; Mdn = 25.0 days, respectively). The wean duration was longer for the 6/14 infants without CHD but with medical diagnoses of gastrointestinal disorders, pulmonary/respiratory disorders, and/or pediatric feeding disorder (Mdn = 63.0 days, IQR = 28.0-90.0). The difference in wean duration was statistically significant when comparing infants with CHD (alone or with other diagnoses) to no CHD plus other diagnoses (U = 8.0, p = 0.046).

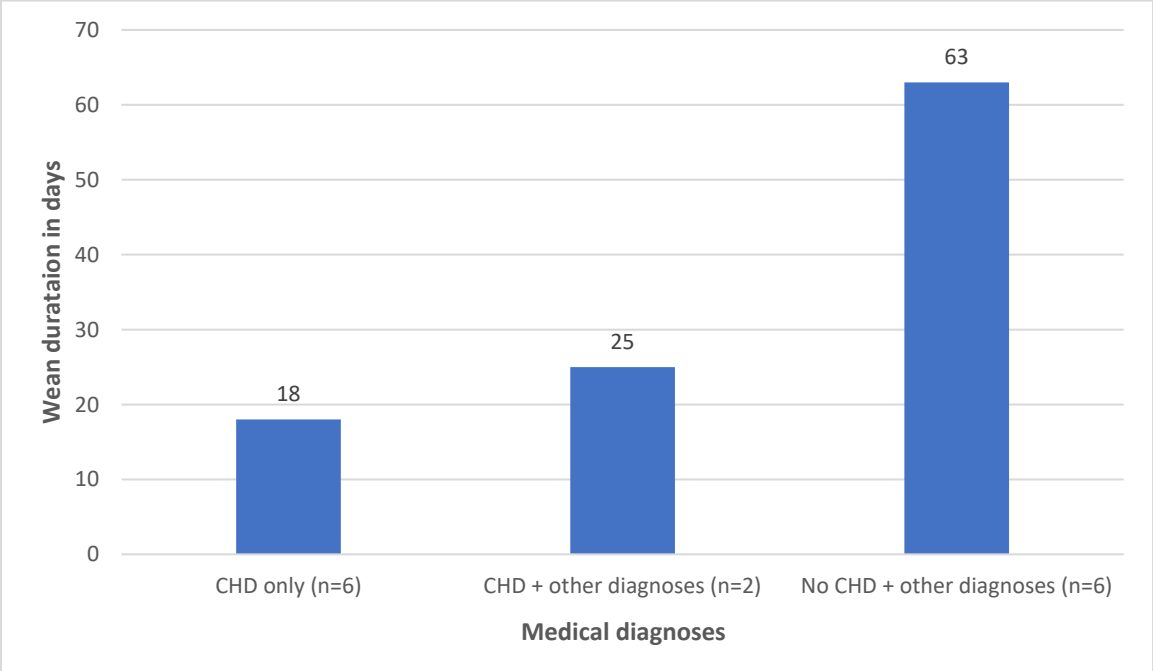

Figure 1 Differences in infant wean duration in days based on diagnoses. Abbreviation: CHD, congenital heart disease.

3.2 Weight

During the wean process, mean weight loss was similar for infants with CHD (as sole diagnosis or with other diagnoses) (M = 6.3%, SD = 2.72) compared to infants without CHD plus other diagnoses (M = 7.2%, SD = 5.44; U = 7.0, p = 0.88). Weight data at 6-months postwean was collected for 12/14 infants. As displayed in Table 3, all 12 infants were gaining weight at 6 months (body weights 6.36-10.0 kg, M = 7.85 kg) with increases over weight at discontinuation of tube feeding between 400 g (6.3%) and 3.64 kg (57.2%) (M = 1.74 kg or 30.1%).

Table 3 Comparison of participant weight prewean, upon discontinuation of tube feeds, and 6 months postwean.

Participant	Weight at prewean, kg	Weight when TF discontinued, kg	Weight at 6 mo. postwean, kg	Amount of weight gain at 6 mo. postwean, kg	Weight gain at 6 mo. postwean, %
1	6.25	6.10	NA	NA	NA
2	6.42	6.9	8.75	1.85	26.8
3	5.0	5.11	6.82	1.71	33.5

4	4.49	4.26	6.53	2.27	53.3
5	6.81	6.36	10.0	3.64	57.2
6	5.9	5.9	7.96	2.06	34.9
7	6.47	6.8	7.95	1.15	16.9
8	7.6	7.3	8.0	0.70	9.6
9	6.5	6.36	9.09	2.73	42.9
10	4.54	4.43	6.36	1.93	43.6
11	6.1	6.7	7.78	1.08	16.1
12	6.2	6.4	6.8	0.40	6.3
13	6.8	6.8	8.2	1.40	20.6
14	8.4	7.53	NA	NA	NA
Mean (SD)	**6.25 (1.07)**	**6.21 (0.99)**	**7.85 (1.10)**	**1.74 (0.89)**	**30.1 (16.89)**

Abbreviations: TF, tube feeding; mo, month; NA, not available

3.3 Quality of Life

Qualitative data related to QOL was collected as part of the postwean survey, which included a free text box for parents/caregivers to describe changes in family QOL postwean. The collected comments were similar for all 3 participant groups, where QOL was described as reduced stress during feeds/meals, freedom from enteral equipment and strict feeding schedules, willingness to try new foods and expressing desire to eat, relaxed family meal-time atmosphere, reduced worry or disappointment about sufficient nutrition, resolution of chronic reflux and vomiting with intrinsic eating, and ability to eat at social gatherings.

4. Discussion

Regardless of small sample size, survey results support the success of GIE home-based weaning for infants with and without CHD. Due to the child-led nature of the GIE wean method, which creates heterogeneity in wean timing and process, we were able to look at participant characteristics by wean time including the participants' age and medical diagnoses. The cohort of 14 infants in this study all weaned off enteral support, with a median wean duration of 28 days. Shine et al. [3] also collected retrospective data on enteral tube weaning of infants with CHD in the home setting using dietetic interventions of reducing feeding volumes, discontinuation of nutrient dense feeds, modification of feeding schedules, or a combination of these interventions. In this study comprised of 30 infants, the median wean duration was longer at 52 days [3]. While this is a longer wean duration, it is difficult to make an accurate comparison as their interventions differ from those used by GIE.

Consistent with earlier studies [19] comparing underlying medical diagnoses, the wean time was significantly shorter for infants with CHD than infants with pulmonary/respiratory problems, gastrointestinal disorders, and/or pediatric feeding disorder who all had similar wean durations. One potential explanation for the shorter wean duration for infants with complex heart conditions as compared to other diagnoses is the requirement that to meet wean eligibility for medical stability, the infant must be fully recovered from recommended age- and weight-appropriate cardiac repair based on their underlying condition. With improved cardiac circulation post-repair, energy requirements can be reduced back to standard ranges for age as the infant no longer needs a

hypercaloric feeding regimen to promote growth. Therefore, infants are able to wean faster because of improved cardiac function which facilitates feeding tolerance and growth.

For the infants with parent/caregiver reported CHD plus other diagnoses, it is difficult to ascertain from our data whether CHD is the primary diagnosis. Since decompensated CHD can cause respiratory and gastrointestinal complications, it is possible that the other reported diagnoses are symptoms of the CHD instead of unique diagnoses. Our data, although limited in sample size, resulted in similar days of wean duration between the CHD only group and the CHD plus other diagnoses group. It remains uncertain whether infants with CHD plus other unique, unrelated diagnoses would demonstrate similar results.

During an enteral wean, weight loss is an expected consequence, with a loss up to 10-15% of total body weight considered acceptable by industry standards [11, 13, 15, 17]. In this study, a maximum weight loss of 10% total body weight was used per GIE policy. Weight loss was similar between the cohort of infants with CHD (this includes those with CHD only and CHD plus other diagnoses) and the cohort of infants without CHD at 6.3% and 7.2% respectively. Weight loss did not impact wean outcomes as all infants were able to successfully transition off EN to an oral diet.

In a recent meta-analysis of tube weaning treatments, Killian et al. [10] found no clear consensus on how tube weaning success is measured. At GIE, “wean success” is defined as the time at which all nutrition and fluid needs are met orally and appropriate growth velocity for age has been achieved. In this cohort, 11/12 infants achieved wean success. The one infant who was not successfully weaned did not meet age-appropriate 6-month postwean growth criteria.

All infants demonstrated growth after coming off tube feeds with a mean weight increase of 1.74 kg or 30.1% at 6-months postwean. However, by GIE definition of wean success, one infant’s wean was not considered successful because weight gain at 6-months postwean was 400 g (for an average daily gain of 2.2 g/day), which is below standards for all ages represented in this cohort of 10-16 g/day for 4-8 months of age, 6-11 g/day for 8-12 months of age, 5-9 g/day for 12-16 months of age, and 4-9 g/day for 16-24 months of age [21]. All other infants, weight at 6 months postwean was up 700 g-3.64 kg (3.9-20.2 g/day) with overall mean gain of 1.74 kg (9.7 g/day) for this cohort.

Enteral feeding is naturally a source of parent/caregiver stress and anxiety [22-24]. Parents/caregivers are responsible for delivering a prescribed nutrition plan with potential for unforeseen complications. Enteral complications range from feeding intolerance to mechanical equipment malfunction [24, 25]. Consistent with data found in the literature [24], GIE has found that during the prewean interview, parents/caregivers frequently report growth struggles despite full tube feeds. Lack of or slow weight gain can exacerbate parent/caregiver stress and worry, resulting in pressured feeds. Subtle pressure, such as presenting the bottle after the infant has signaled they are not interested or chasing the infant’s mouth with the bottle, or overt pressure, such as holding the bottle firmly in the infant’s mouth or using distraction during feeds, can result in feeding refusal. Learned or acquired feeding refusal is the infant’s adaptive response to feeding pressure.

In GIE-led weans, parent/caregiver engagement with a mental health social worker prior to starting the wean, coupled with ongoing support from the social worker and parent coach while weaning, provides parents/caregivers with the tools to cope with feelings of stress and anxiety. Based on author observations, support from the interdisciplinary team may mitigate pressured feeds and result in positive feeding behaviors, contributing to the successful transition from EN to an oral diet.

Studies have shown that QOL improves as the child transitions from enteral to oral feeds [26]. While there was no prewean QOL data collected in this survey, parents/caregivers were provided a free text box to subjectively compare their QOL postwean. The most common QOL indicators reported included reduced mealtime stress, liberalized feeding schedule, increased exploration and consumption of food, and resolution of symptoms of feeding intolerance.

Based on our interactions with parents/caregivers, there is no global standard of practice for how long to keep the feeding tube in place after weaning. A recent position paper by Clouzeau et al. [5] recommend nasogastric tubes be removed as soon as oral intake meets 75% of daily needs compared to waiting 6 months after discontinuation of tube feeds and feeding autonomy achieved before removal of a gastrostomy tube. Further evaluation is needed for infants and children with CHD to determine whether there is sufficient benefit to keeping the feeding tube in place knowing there could be upcoming surgeries versus removing the feeding tube in the interim if the infant is otherwise medically appropriate. Potential benefits to keeping the tube must be weighed against family stress, cost, and potential medical complications of maintaining the tube.

Study limitations include 59% unreturned surveys, potential for recall bias based on retrospective data collection, inability to calculate weight-for-age z-score due to deidentified data, and incomplete data collection for some surveys. There is an increased likelihood that parents/caregivers who perceived their infant was less successful with weaning were less likely to return the survey, thereby potentially skewing the data positively. GIE is reliant on local medical teams for diagnosing CHD using their institution specific criteria and self-reported by parents/caregivers on the intake form.

5. Conclusions

We conclude that infants with CHD are good candidates for enteral weaning and in this preliminary study demonstrated an ability to wean more rapidly than those without CHD when using a child-led approach to enteral weaning. In order to support these observational findings, additional studies are required and should include a larger sample size, data collection for infants and children, longer study period, and qualitative interviews to enrich the quality of the data specific to individual experience.

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Author Contributions

Lisa Grentz and Dr. Kristin Furfari equally contributed to the conception and design of the research; Lisa Grentz acquired the data; all authors contributed to data analysis and interpretation of the data. All authors drafted the manuscript, critically revised the manuscript, agree to be fully accountable for ensuring the integrity and accuracy of the work, and read and approved the final manuscript.

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Competing Interests

Lisa Grentz and Dr. Kristin Furfari serve as paid consultants to Growing Independent Eaters (GIE) and are part of the medical advisory board. Rebekah Keifer is a co-owner of GIE and receives a salary from GIE.

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