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ORIGINAL ARTICLE

Transition from tube feeding to oral feeding: experience in a tertiary care paediatric cardiology unit

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Abstract

Background Home enteral tube feeding (HETF) is imperative for many infants and children with congenital heart disease (CHD). Tube weaning (TW) facilitates the progression from tube feeding to oral diet. There is limited literature on TW practices, protocols and success for children with CHD that have been tube fed.

Aims The objective of this study is to assess the process of weaning HETF in a tertiary referral centre for paediatric CHD. Specifically, we aimed to assess the duration of HETF, duration of TW and the interventions involved.

Methods We retrospectively reviewed the medical and dietetic records of all infants and children that were successfully weaned off HETF over a 12-month period from January 2015 to December 2015.

Results There were 30 children included in the study, 9 boys and 21 girls. The diagnoses included 15 septal defects, 8 univentricular diagnosis and other diagnoses in 7 children. The median age at initiation of enteral tube feeding was 45 days (range 2–169). The median duration to wean from enteral tube feeding was 52 days (range 2–359). Number of dietetic consults required for successful TW varied among patients, median 5 (range 2–23). The number of days required for successful TW was associated with age and duration on HETF. Dietetic interventions included discontinuation of nutrient dense feeds, altering feed schedule and reduction of feed volume.

Conclusions Weaning HETF is possible in the outpatient setting. Early and frequent dietetic intervention is recommended to ensure prompt discontinuation of HETF when appropriate.

Keywords Congenital heart disease · Home enteral tube feeding · Tube dependency · Tube dependent · Tube feeding · Tube weaning

Introduction

Congenital heart disease is the most commonly occurring congenital abnormality and affects approximately 8 per 1000 live births [1]. The defects are generally classified into cyanotic and acyanotic congenital heart disease. There is huge range of severity ranging from minor anomalies to very complex abnormalities that have a lifelong impact on the life of the child [2]. Life expectancy has improved with recent advances in foetal diagnosis, perinatal care, cardiovascular anaesthesiology, and surgery [3]. Significant growth failure is well recognised in this patient group. Multiple studies outline the feeding difficulties that children with congenital heart disease experience [4–7]. Home enteral tube feeding (HETF) is imperative for many infants and children with congenital heart disease. Rates of HETF in this group have been reported as high as 45% [5–8]. The indications for HETF are most commonly due to an imbalance in calorie intake versus requirements, suboptimal weight gain, risk of aspiration and often a combination of some or all the above. Tube weaning (TW) is a process that facilitates progression from tube feeding to oral diet. TW is often explored by parents, carers and the multidisciplinary team once a child is medically and nutritionally stable. Children often reach this point when their cardiac defect is surgically repaired and when there is no medical indication for HETF. Despite tube feeding being a short-term necessity, many children still struggle to progress to full oral feeding and become tube dependent. Tube dependency (TD) is recognised as an unintended complication of tube feeding in young children [9].

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Infancy is a critical period for development of oromotor skills. Many infants who require neonatal cardiac surgery or who have complex congenital heart disease (CHD) do not develop the skills to feed orally [10]. Others will lose their oral skills while tube feeding or during periods of illness. Lack of oral feeding during infancy leads to deficits in cortical development as motor and sensory pathways between the oropharynx and the cortex are not established [11]. Also, symptoms of congestive cardiac failure are often an underlying problem and a barrier to oral feeding. This may be compounded by other factors such as aspiration, vocal cord palsy and reflux [10].

Establishing oral nutrition is critical for normal development, speech and communication. It is not surprising that infants with complex congenital heart disease that require device-assisted feeding have been found to be at increased risk for neurodevelopmental delay [5]. The ability to achieve full oral feeding is one of the most significant factors associated with the developmental process in children with congenital heart disease [5]. TD has a negative impact on quality of life for children and their families [5, 12]. The practical challenges, burden of care and psychosocial issues associated with HETF have been well documented [10, 12].

To minimise the myriad of complications associated with TD, timely tube removal is imperative where possible. Unfortunately support and resources available for families of children on HETF vary and are often suboptimal [13]. TW facilitates progression from tube feeding to oral diet. It is not surprising that it often becomes a frustrating challenge for parents, carers and healthcare professional to establish oral feeding following periods of prolonged tube feeding.

Several TW and feeding programmes have been established over the past two decades, but only few with detailed outlines and definitions of terms have been published [14–16]. Many programmes consist of intensive outpatient or even 2- to 3-week-long inpatient stays [17–19]. Inpatient programmes often vary in methods, structure and goals [19]. The Graz model is one of the more published TW programmes [14]. It has been internationally recognised as a rapid and effective TW programme. This programme uses a combination of therapies and interventions, including the reduction of the nutritional contribution from tube feeds. Hunger provocation has been found to be one of the most effective intervention for some patient groups with a success rate of 86% [18]. Behavioural interventions have also been found to be highly effective and safe for transitioning long-term tube feeding children to oral feeding [17]. Moreover, children maintained nutritional stability at 1-year post treatment. In 2014, a study was published on the benefits of TW via net coaching [20]. This novel approach demonstrated similar efficacy to onsite TW intervention programmes. Home-based treatment programmes have been found to be safe and a promising new modality for managing infants TD [15]. Results of a review completed by Wilken et al. found that the success rate of home-based treatment programmes was consistently 90% of the involved cases, with major improvements in eating behaviours and without deceleration of growth [15]. The potential advantages of home-based and outpatient TW programmes for the hospital are cost and preservation of acute hospital beds. The benefits for the child and family involved are parental empowerment, cost and minimal disruption to family life.

In response to the increasing number of children becoming TD, an inpatient TW programme based on the Graz model was established in Our Lady's Children's Hospital, Crumlin (OLCHC), in 2008 [21]. During the period of September 2008–December 2009, 51 patients were enrolled in this intensive paediatric tube weaning programme, of which 32 children had primary diagnoses of congenital heart disease. The average length of hospital stay was 20 days. The success rate was 88% with 45/51 participants successfully tube weaned. The average age on enrolment to the programme was 21.5 months. The mean percentage weight loss on discharge post the TW programme was 8.1%.

Following the introduction of the OLCHC inpatient TW programme, there was an increased awareness regarding the issue of TD in the cardiac and dietetic departments. TW in the outpatient setting was gradually explored. There was also a focus on earlier intervention.

The objective of this study is to assess weaning HETF by dietetic interventions among children with congenital heart disease in an outpatient setting. The setting for this study was OLCHC, the national tertiary referral centre for paediatric cardiology. We aim to give a brief outline of our HETF service. We will investigate factors affecting successful TW, dietetic interventions required, weight for age z score (WAZ) changes and cost analysis.

Methods

A retrospective review of all infants and children with congenital heart disease that were successfully weaned off HETF in the outpatient setting during the period January 2015 to December 2015 was conducted in OLCHC, Dublin, Ireland.

Children discharged on HETF from OLCHC are added to an active dietetic database. While on the active database, each child is under the care of the dietetic department in OLCHC. Conversely, children are removed from the database once HETF is discontinued, when dietetic care is transferred to another centre or if the child dies. Therefore, this database is in a constant state of flux. This review looked at the numbers of children discharged from OLCHC during the period January 2014 through to December 2016. Data was then analysed from records of infants and children that were successfully weaned off HETF in 2015. The children included

were identified by the dietetic database. All were followed up routinely by the dietetic department.

The criteria for commencement of TW included medical stability, completion of corrective cardiac surgery or stage 2 palliation (Bidirectional Glenn procedure), adequate nutritional status and evidence of appropriate oral skills as assessed by speech and language therapy (SALT) where appropriate. Both partial oral feeders and tube-dependent children were included. The medical team were consulted regarding the suitability of TW where appropriate. Each family received practical nutritional advice and counselling. There was an emphasis on transitioning to age appropriate family foods. Many infants and children did not meet the criteria for TW and thus remained on the HETF database.

Data was collected retrospectively from the medical and dietetic records. Demographics were recorded, including congenital cardiac diagnosis. Diagnosis was subdivided as septal defect, univentricular heart or other. Oral aversion was defined as reluctance, avoidance, or fear of eating or drinking or accepting sensation in or around the mouth.

Age on commencement of HETF and total duration on HETF was analysed. Age on commencement of TW plus completion of TW process was analysed. The duration of the TW process was calculated.

Anthropometrics were collected at birth, pre-TW and post feeding tube removal. WAZ scores were subsequently calculated using the appropriate references [22–24]. WAZ at birth, on commencement of TW and on completion of TW was calculated.

Patient contact statistics were analysed using the hospitals patients' administration system, version 2017. The frequency of dietetic contacts and consultation time required were quantified. Cost analysis was based on the most recent national statistics [25].

The frequency of three common dietetic interventions were analysed.

1. Discontinuation of nutrient dense feeds. Feeds were changed to standard formula or unmodified expressed breast milk.
2. Modification of feed schedules. This involved changing feeding routine, e.g. stretching feeding intervals (e.g. from 3 to 4 hourly) or decreasing frequency of feeds.
3. Feed volume reduction: Volumes were initially reduced to 100 ml/kg. Further reduction in volumes was completed in consultation with the medical team. Hydration was carefully monitored during this time period.

Statistical analyses were performed on IBM SPSS Statistics version 23. Categorical data is presented with numbers and their accompanying percentages, *N* (%). As the age of children and duration of HETF and TW is not normally distributed, this data is presented as medians (min-max). WAZ scores are presented as mean (SD). Distribution was checked using Mann-Whitney *U* Test (duration of weaning) $p = \leq 0.001$. Correlations were tested using Spearman. Statistical significance was achieved for $p = < 0.005$.

Results

Analysis of the dietetic database showed that a total of 157 infants and children were discharged on HETF from the Children's Heart Centre, OLCHC from January 2014 to December 2016. On average 52 children per year require HETF on discharge from the Children's Heart Centre. We identified 30 children that met the inclusion criteria (successful TW) over the 12-month study period, 2015. All children included commenced tube feeding post neonatal cardiac surgery or prior to cardiac surgery in later infancy. Demographics are summarised in Table 1. There were a higher number of female ($n = 21$, 70%) infants compared with males ($n = 9$, 30%). The majority of children had septal defects ($n = 15$, 50%), which included 5 (16.6%) atrioventricular septal defects (AVSD) and 10 (33%) ventricular septal defects (VSD). The remaining children ($n = 7$, 23%) were classified as other. Preterm infants (< 37 weeks gestation) accounted for 16.6% ($n = 5$) of infants. Eleven children (36%) had a genetic

Table 1 Demographics

Variable	*n*	%
No. of patients included	30	100
Male	9	30
Female	21	70
Gestational age		
Full term	24	80
Premature < 37 weeks	6	20
Diagnosis		
Univentricular	8	26.6
AVSD	5	16.6
VSD+/−ASD	10	33.3
Other	7	23.3
Genetics		
Nil	19	63.3
Trisomy 21	10	33.3
Turner syndrome	1	3.3
Oral intake pre-TW		
Nil oral feeding (tube dependent)	20	66
Partial oral feeding	10	33
Type of feeding tube		
Gastrostomy	2	6.6
Nasogastric	28	93.4

Table 2 Indications for HETF

	n	%
No. of patients included	30	100
Low energy intake: energy expenditure ratio	16	53
Risk of aspiration	6	20
Poor weight gain	17	56.6
More than 1 indication	8	26.6

syndrome diagnosed, of which 10 infants had karyotype confirmed as Trisomy 21.

The indications for HETF are categorised as poor weight gain, low ratio of energy intake to energy requirements and risk of aspiration (see Table 2). Some had more than one indication for HETF. Table 3 depicts the median (min, max) age on commencement of HETF and TW. Table 4 depicts the median (min, max) duration of HETF and of the TW process.

Figure 1 displays the strong positive association between the duration of TW and duration of HETF ($r = 0.92$, $p = \leq 0.001$). Figure 2 displays the strong positive association between duration of TW and age on commencement of TW ($r = 0.72$, $p = \leq 0.001$).

Dietetic interventions used during the TW process were analysed (Table 5). Children were then reviewed by dietetics post removal of nasogastric tube or post cessation of gastrostomy feeds. Two infants (6%) lost weight at their first follow up. The overall mean weight loss was 24 g. Table 6 displays mean WAZ at birth, on commencement of TW and at follow-up post tube removal. The mean WAZ score improved post tube removal. Twenty (66%) children within the study group met the criteria for oral aversion. Median duration for TW was 11 days longer for orally aversive infants (Fig. 3).

The number of combined dietetics reviews for the TW process alone amounted to 197 contacts. The median number of dietetic contacts during TW was 5 (range 2–23). The frequency of contacts averaged one review every 11 days during the TW process. OLCHC was the primary care centre for 11 (37%) of the group.

The cost of 5 dietetic cardiac outpatient reviews is approximately 75 euro. This estimated cost is based on a senior dietitian salary scale and an average outpatient contact time of 25 min. Although specific costs for a TW admission day are not available, the Health Service Executive's (HSE) Public Hospital Cost Report [25] state that the mean cost of an inpatient admission day to a paediatric tertiary referral centre is 2025.45 euro per day. The average length of stay for OLCHC's inpatient tube weaning was 20 days [21]. Therefore, the estimated cost of inpatient TW would be 40,509 euro. TW in the outpatient setting would result in a significant cost saving in comparison to the estimated cost of inpatient TW.

Table 4 Duration of HETF and TW

	Median (no. of days)	Minimum–maximum (no. of days)
Duration of HETF	202	56, 669
Duration of TW	52	2, 359

Discussion

Children born with congenital heart disease are at risk of malnutrition and growth stunting prior to surgical repair [26]. Chronic malnutrition is associated with inferior clinical outcomes in children undergoing congenital cardiac surgery repair [27]. In addition, undernutrition leads to poor growth which is in turn associated with delayed mental development, poor school performance and reduced intellectual capacity [28]. HETF is associated with improved weight gain in children with congenital heart disease and is a necessity for many [29]. The children included in this study had open heart surgery requiring cardiopulmonary bypass as a neonate or as an older infant. Some children had lesions that necessitate one surgical intervention, whereas the children with univentricular physiology require a three-stage surgical reconstruction. Timing of cardiothoracic surgery will depend on many factors for example, the type of defect, age and size of the child involved. Many remain on HETF post operatively as feeding difficulties are common in children before and after surgery [4] and some of these children become TD. TD as previously discussed has many negative health, psychosocial and economic-related consequences [30]. This retrospective study found that weaning from HETF is possible for some children in an outpatient setting following cardiac surgery.

The duration of TW was extended in older children and in those that were tube fed for longer periods. Our study concurs with Ishizaki and colleagues, where they found that weaning from tube feeding at earlier ages is more efficient [31]. We propose potential reasons for this. Firstly, illness and tube feeding during the first 6 months even first year of life have

Table 3 Age on commencement of HETF and TW

	Median (no. of days)	Minimum, maximum (no. of days)
Age on commencement of HETF	45	2, 169
Age on commencement of TW	189	90, 354

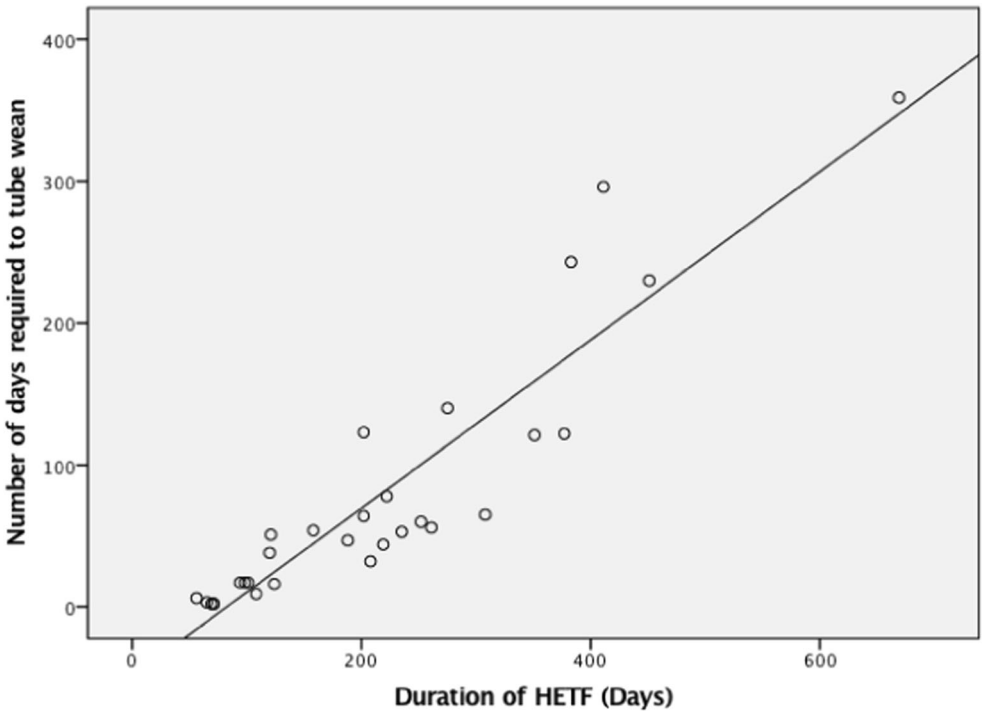

Fig. 1 Correlation between duration on HETF and duration of TW

a huge impact on a child's development and particularly oral development [11]. It is a sensitive period for developing feeding skills and exposure to new foods. Delayed oromotor skills, cognitive development and oral aversion will negatively affect a child's ability to feed. It is not surprising that TD occurs. Secondly, the fear of new foods also known as the neophobic response peaks at 20 months. As the prevalence of picky eating increases with age, it is understandable how modifying feeding behaviour becomes more challenging in older children [32]. Early intervention is crucial in ensuring prompt discontinuation of HETF when there is no medical indication.

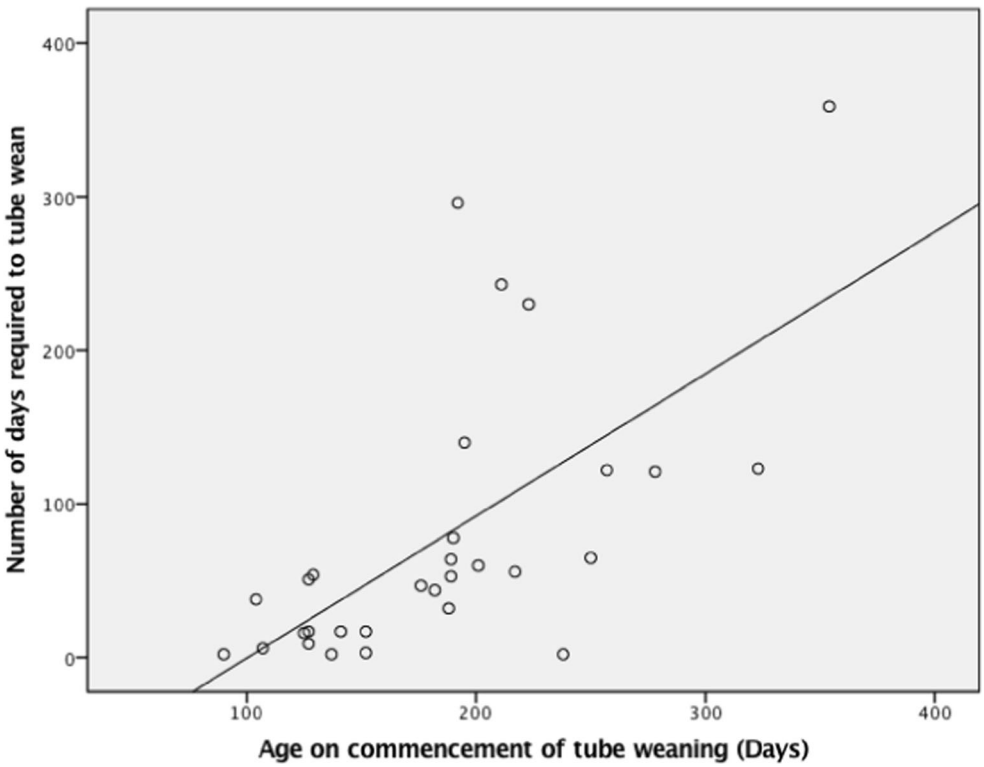

Fig. 2 Correlation between duration of TW and age on commencement of TW

Table 5 Dietetic interventions used during TW process

	n	%
No. of subjects included	30	100
Interventions		
Discontinuation of nutrient dense feeds	24	77
Alteration of feed schedule	15	48
Reduction of feed volume	29	93
Combination of all three interventions	18	60

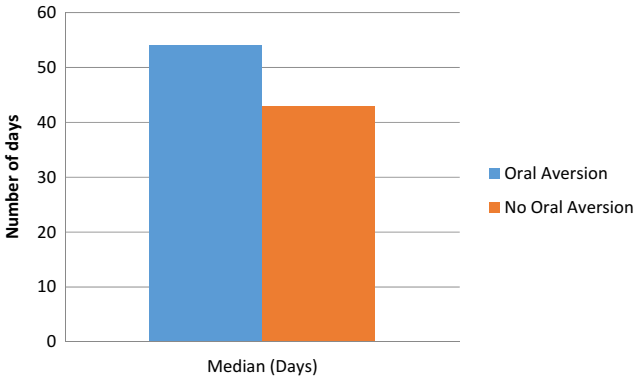

Fig. 3 Duration of TW in children with oral aversion and without oral aversion

This gradual approach to TW was associated with maintenance of normal growth and minimal weight loss. This is reassuring as rapid and excessive weight loss is often a concern during the tube weaning process [15]. Our results are encouraging as WAZ improved on cessation of tube feeds.

In this study, successful transition to oral diet and fluid was facilitated by adjusting feed volumes, discontinuation of nutrient dense feeds and altering feed schedules, or a combination of approaches. These strategies may provide guidance to others working in this area. Regular dietetic reassessment of nutritional requirements and the indication for nutrient dense feeds is essential for this patient group. Underfeeding can lead to poor growth. Overfeeding can lead to increased weight gain, worsening oral aversion and tolerance issues. Total energy expenditure (TEE) varies considerably in infants and children with congenital heart disease. Increased TEE is associated with symptoms of congestive cardiac failure. Symptoms are dictated to by the severity and type of lesion. For example, a preoperative cardiac infant may require up to 120–140 kcal/kg [33, 34]. In the normal population, energy requirements per kilogramme decrease with increasing age [35]. Therefore, it is not surprising that energy requirements change considerably post operatively in congenital heart disease and with increasing age. The calorie requirement for 6- to 12-month-old infant post corrective cardiac surgery may drop to 72 kcal/kg [35]. As children on HETF cannot regulate their intake close monitoring and attention to actual nutritional intake is required. The indication for nutrient dense feeds should be regularly reassessed. It is a fine balance to provide adequate nutrition support for growth and still maintain oral skills.

Tube feeding in children is associated with a number of complications, which include oral aversion [36]. The development of TD can be minimised if typical symptoms are recognised early and effective TW is implemented [37]. A large proportion of this group were orally aversive. The length of time for TW was extended in the aversive group. The promotion and preservation of oral skills should be a priority for infants and children that are tube fed, aiming to minimise oral aversive behaviours from the outset. In those at risk of aspiration, oral stimulation may help lessen the level of oral aversion. Oral stimulation has been shown to have many positive outcomes in preterm infants [38]. A recent publication has investigated the impact of oral motor intervention in infants with complex congenital heart disease [10]. More intensive study is necessary to evaluate strategies to improve oral feeding outcomes in children with congenital heart disease. Nevertheless, in all individuals where it is medically appropriate, efforts should be directed at promoting oral skills and positive oral experiences.

Frequent and early dietetic follow up is required to successfully tube wean infants and children post operatively. At least one dietetic review per 11-day period was required for successful TW in this population. This has implications for the workload and resources of dietetic departments. The estimated cost associated with outpatient dietetic reviews is remarkably less than the cost of an inpatient admission for TW. TW in the outpatient setting is cost-effective while also preserving acute hospital beds. Most importantly avoiding a hospital admission for TW minimises the disruption for the patient and family. This study demonstrates how our cardiac HETF service has evolved. Admission for inpatient TW is now a rarity and is only instigated post trial of TW in the outpatient setting first.

There are a number of limitations to this study. This retrospective study found that weaning from HETF is possible in an outpatient setting following cardiac surgery. A shortcoming of this study of is that it only describes cases that were successfully weaned off HETF in the outpatient setting. It does not investigate or describe the outcomes related to the remainder of children on the HETF database. These children may not have been medically stable for TW in the first instance or others may have failed to transition to oral diet. Further analysis of this database is warranted. Additional exploration into

Table 6 Weight for age *z* score at specific time points

	Mean ± std. dev	Range (min, max)
WAZ birth	− 0.42 ± 1.05	− 2.64, 1.69
WAZ on commencement of TW	− 1.33 ± − 1.06	− 3.88, 1.42
WAZ on completion of TW	− 1.26 ± 1.13	− 3.91, 2.1

how some children progress to diet earlier than others is also necessary. Such research would help our understanding of this complex issue. We report the nutrition interventions only and the estimated cost associated with these alone. SALT provided support to a large proportion of this group through regular outpatient consultations that were often held in conjunction with dietetics. They also offered messy play sessions and advice on oral stimulation programmes. Their input was pivotal in successful TW. Unfortunately, supplementary support from other disciplines such as psychology and occupational therapy were not always available for our patient cohort. According to Wright and colleagues in 2011 [39], teamwork and collaboration is vital to support the family during their transition to oral feeding. Since TW can be difficult, it is best accomplished with a multidisciplinary approach, including health care professionals in the field of paediatrics, dietetics, psychology, SALT and/or occupational therapy [14, 30]. Methods for extracting the true cost associated TW in both the inpatient and outpatient setting are not very advanced in today's healthcare system. We acknowledge that the methods used in estimating cost in our study were crude. Long-term growth and feeding outcomes were not assessed in this study. Also, the findings here are specific to infants and children with congenital heart disease in a single centre. This population of HETF patients are unique as many post corrective cardiac surgery may no longer have a medical indication for tube feeding. This may not reflect the normal population of children receiving HETF.

With more proactive nutrition support, advancing medical care and improved surgical techniques, an increasing number of children now require HETF as part of their treatment. A multidisciplinary and holistic approach is imperative to ensure children and families are supported during this time. We agree with other authors that prior to HETF being commenced, a plan must be generated covering maintaining oral skills, expected timeframe for HETF and method for TW [37]. Oral feeding outcomes post cardiothoracic surgery should be assessed more frequently. Such data would provide important information in relation to the quality of life and neurodevelopment of these children.

Conclusion

Dietetic interventions can be successful in TW children with congenital heart disease. We recommend that on the basis of these results that the gradual approach to TW should be trialled initially before instigating an admission for TW. Early and frequent dietetic input is vital. TW in the outpatient setting is cost-effective while also minimising the disruption to the family involved.

Compliance with ethical standards

Conflict of interest The authors have no conflicts of interest relevant to this article to disclose.

Informed consent This study complied with guidelines from Our Lady's Children's Hospital Ethical Committee. Informed consent was not obtained as this was a retrospective observational study.

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