

Mealtime Support: A Pilot Case Series study of an Effective, Cost-saving Outpatient Hunger-Based Feeding Program for Tube Dependency

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ABSTRACT

Background: Tube feeding is essential for children who cannot meet nutritional requirements orally. Over time, this can lead to tube dependency with negative impacts on the quality of life of children and families.

Objective: We aimed to examine the efficacy of a multidisciplinary child-led, hunger-based approach called “Mealtime Support” at the Stollery Children’s Hospital in Edmonton. Nutritional outcomes, parental satisfaction, and cost implications were evaluated over 9 months postprogram completion per child.

Methods: The ambulatory meal program was delivered 2–3 times a day, for 2 weeks, by an occupational therapist and dietitian, under medical supervision. Hunger was promoted by reducing tube fed calories by 80% before commencement. Caregivers completed 12-question subjective surveys pre- and postintervention. Microcosting methods compared costs between the program and ongoing tube feeding.

Results: From 2016 to 2017, 6 children were enrolled and 5 completed the program. At 1-month postintervention, 4/5 of the children were 100% orally fed. Parents reported improvement in mealtime struggles ($P = 0.005$), reduction in worry about their child’s eating ($P = 0.005$), and improvement in their child’s appetite/variety foods eaten ($P = 0.004$). Over 2 years, the potential cost savings were estimated at \$43,471.00. By 6 months, all feeding tubes were removed.

Conclusions: Mealtime support was safe and successful in reducing tube dependency and cost-effective compared to no intervention or hospital based programs, which suggests that there is a need to develop and fund Canadian outpatient feeding programs.

Key Words: feeding program, tube feeding, tube dependency, tube weaning, clinical hunger provocation

INTRODUCTION

Tube dependency is defined as “the active refusal to eat or drink, lack of motivation or inability to learn, or showing no precursors of eating development and skills after long-term enteral feeding” (1,2).

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The authors report no conflicts of interest.

Ethics approval was obtained for the conducting of this study

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Tube dependency greatly impacts the quality of life of children and families and is a significant burden to the health care system (2). Economic challenges, increased burden of care, and psychosocial issues all reinforce the need for timely tube removal.

Home-based treatment of feeding tube dependency and feeding tube weaning were first established in Germany in 2005 (3). Other established feeding programs include the following: the Newborn Individualized Developmental Care & Assessment Program (NIDCAP) (4). The Sequential Oral sensory (SOS) Approach to Feeding (5), the Satter Eating Competence Model (6), and programs worldwide in places such as Austria (7), the United States (8), the Netherlands (9), and France (10). Many programs consist of intensive outpatient or even two to three weeklong inpatient stays. British Columbia (BC) Children’s Hospital (11) and Montreal Children’s Hospital (12) are the only two dedicated ambulatory clinics for feeding disorders currently in Canada; however, there are currently no studies published on the methods and effectiveness of pediatric feeding programs within Canada that support tube weaning.

The Canadian Pediatric Society (CPS) and American Academy of Pediatrics (AAP) have guidelines on the provision of enteral nutrition support, but there are none specifically for tube weaning (13,14). The CPS and AAP guidelines state that nasogastric tube feeding is not appropriate for long-term home nutrition support and recommend gastrostomy tubes for nutrition support predicted to last 2–3 months or more. A 2010 survey of pediatric health care providers at our institution demonstrated that 73% of pediatric health care practitioners were unaware of these guidelines and 47% would consider a gastrostomy tube only after 3–6 months. At our center, the duration of both nasogastric and gastrostomy tubes feeding is prolonged for a significant number of children. The average duration before discontinuation or conversion to a G tube was 114 days (range 2–608 days) (Figure 1). These data were based on a clinical audit of consecutive patients referred to our Pediatric Home Nutrition and Support Program (PHNSP) for tube feeding from January 2014 to December 2015. While 69% of children with a nasal tube successfully wean off of tube support, 47% exceeded the CPS recommended duration of 3 months and 25% had the nasal tube for more than 6 months, before they either weaned or converted to a gastrostomy tube. This prolonged duration of tube feeding is both highly costly to our institution and a burden on the children and their families.

Our institution’s current practice to address tube dependency is not formalized. The PHNSP at the Stollery Children’s Hospital in Edmonton, Alberta, serves ambulatory patients located north of Red Deer, Alberta. Children are followed by phone, telehealth, and in-clinic visits. While all patients are seen regularly by a nurse, dietitian, and feeding therapist, the team guides tube weaning in conjunction with the family according to their clinical judgment and perceived psychosocial and nutritional readiness of the child and family. To address the need for a more structured approach, a child-centered program called “Mealtime Support” was initiated at the Stollery Children’s Hospital. Utilizing a hunger-based approach similar to the Graz model (15), the eligibility criteria and approach in

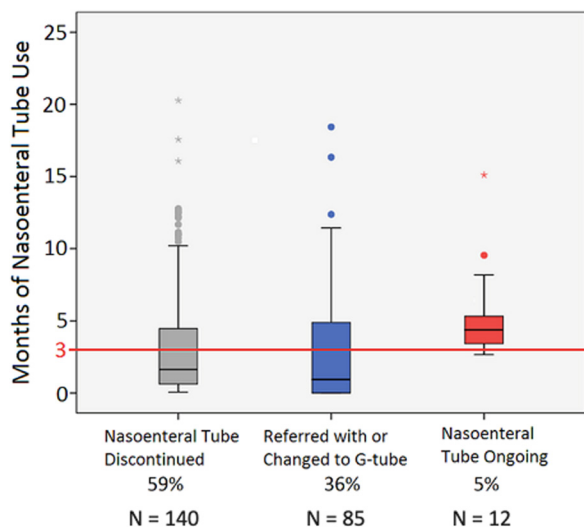


FIGURE 1. Duration of tube use among enterally fed pediatric patients ($n = 237$) at the Stollery Children's Hospital 2014–2015.

the outpatient setting was patterned after the tube weaning programs in Seattle and Vancouver. This 2-week intensive intervention was designed to encourage self-regulated oral intake and teach children that eating is a solution to hunger.

The primary aim of this study was to demonstrate the feasibility and effectiveness of Mealtime Support, including parent satisfaction and cost benefit. A secondary aim was to determine the number of pediatric hospital admissions and gastrostomy tube insertions from 2008 to 2019, per province, from the Canadian Institute for Health Information (CIHI). We hypothesized that there is a rising number of tube dependent children across Canadian provinces, which would justify support for weaning programs (like Mealtime Support) in our center and Canada wide.

METHODS

This pilot study was approved by the institutional review board at the University of Alberta (ethics number: PRO00106151). Signed informed parental consent was obtained for each participant.

Approximately, 20 children were submitted by their PHNSP team as eligible for this program and the first 6 consecutive children were enrolled in Mealtime Support from December 2016 to December 2017. Of the remaining 14 children, one child was ineligible for the program due to a medical comorbidity. The other 13 were all excellent candidates for the program and were waitlisted. Children were referred to the program by their PHNSP care team and screened for eligibility by the program physician (JT). Criteria for eligibility included: feeding tube dependency, with prior unsuccessful attempts to tube wean during the course of the standard care provided by the multidisciplinary teams. The patient had to be bolus fed, considered medically stable and safe for oral eating. Social stability was also required, meaning no major changes at home. All of our patients lived with both of their parents and did not have a new sibling born in the past year or being born in the coming year. Finally, the child had to be familiar with home mealtime routines and comfortable around food.

Children selected were seen in clinic by their pediatric gastroenterologist (JT), occupational therapist (AV), and registered dietitian (CP) 1 week before starting. At this time, a physical assessment, meal observation, and nutritional assessment were completed. There

was a physical examination done by their medical provider (JT) who reviewed their medical history. No additional bloodwork was required. Their dietician (CP) also assessed their caloric needs and which percentage they were taking in orally and via G tube. Before starting, children had a medically approved rapid reduction in calories (-80%) and fluids (-20%) over 4 days to promote hunger and interest in eating. Families were given a printed reduction schedule, and food records were provided and recorded by the family starting from day 1 of calorie reduction. Feeding sessions were conducted by the occupational therapist and dietitian, 2–3 \times /day, 5 days per week. Sessions were individualized and modeled after the families usual meals. Behavioral interventions were used to help increase oral intake and reduce the fear of swallowing (16) through structured meals, social modeling, and positive reinforcement (17). Top-off tube feeds were given immediately upon completion of each meal/snack and were provided at the table. Children were weighed 3 \times /week. Oral intake was recorded daily and analyzed by the dietitian using Food Processor 11.0.3. Mealtime Support was discontinued if the child lost more than 10% of their weight in a week.

The child and at least one caregiver participated daily in the program for 2 weeks (Monday–Friday), 3 \times /day (breakfast/lunch/snack). Siblings and other family members were also encouraged to participate. Breakfast and lunch were more structured, while the focus of the afternoon session was on food play. Based on the child's interest, mealtime sessions took place in an outpatient ambulatory clinic setting but some sessions took place at other locations such as at home or daycare. The goal was to equip parents and caregivers with strategies that they could apply at home. After several sessions in the ambulatory clinic, the child had their remaining meals at home, and parents were responsible for providing the same mealtime routine and tracking their child's oral intake.

Nutritional outcomes and weight were evaluated over 9 months following completion of program a follow up assessment was made by the dietician

Caregiver Survey

Both caregivers for each family were asked to complete a 12-item survey around mealtime experiences pre- and postprogram completion (Table 3). The survey was developed based off of the psychometric properties of the Brief Autism Mealtime Behaviors Inventory (BAMBI) (18). Although BAMBI was developed for children with autism, many of the variables surrounding mealtime behaviors were easy to understand and analogous to our tube dependent population.

Micro-costing Analysis

A micro-cost analysis was performed by calculating basic resource utilization for ongoing tube feeding over a year, as compared to the defined costs of the Mealtime Support program over the 2 weeks. The costs of ongoing tube feeding in the program used 2017 fiscal year data (April 1–March 31). To calculate the total annual costing per patient, we looked at formula cost, supply costs, delivery cost, pump cost (total cost of pump divided by 5 years), 3 gastrostomy tubes per year, 2 clinic visits a year with 3 staff members.

CIHI Data

Data obtained from CIHI included the number of pediatric (<18 years old) hospital admissions and gastrostomy tube insertions in Canada, collected from Discharge Abstract Dataset metadata and National Ambulatory Care Reporting System between 2008 and 2019. The specific CIHI codes used for this data search included: the number of internal devices implanted in the stomach (I.NF.53) surgically and with interventional radiology but excluded gastrostomy tubes implanted endoscopically: per orifice approach (I.NF.53.CA-TS), using endoscopic per orifice approach (I.NF.53.BA-BC)

and using endoscopic per orifice approach of barrier device (e.g., ValenTx implantable device) (1.NF.53.BA-ES). Among Canadian pediatric GI centers, as far as we are aware our site is the only one placing gastrostomy tubes endoscopically and so small subset of tubes placed endoscopically at our center were not included in the CIHI data set.

Statistics

Pilot data are shown descriptively per individual patient. Survey outcomes pre- and postprogram were evaluated using student *t* tests. Multivariate linear regression modeling examined the CIHI data for prediction of number of gastrostomy insertions per 100 000 pediatric population by province and time (year), corrected for the total pediatric population and number of admissions in each province per year. Analysis used SPSS and significance was set at $P < 0.05$.

RESULTS

Six children (3 girls–3 boys, aged 14 months–8 years) participated (Table 1). Before commencing the program, patients were taking 0–30% of their nutrition orally and on average had been tube fed for 57 months (range 18–95 months). Five patients completed the program; one patient had to discontinue due to excessive weight loss

(Table 2). In the five children who completed the program, no weight loss was observed by 9-month follow-up (Table 2). The oral intake over time for all patients is shown in Figure 2. At 1 month after the program 4 patients took 100% of their nutrition orally, one patient was 100% orally fed by 5 months and the remaining one patient continued to be tube fed (Table 2).

Survey

Ten parents completed the survey at intake and program completion. There was a statistically significant improvement ($P < 0.05$) postintervention in 8 of 12 areas by both primary caregivers. Caregivers reported significant improvement in mealttime struggles ($P = 0.005$), reduction in worry about their child's eating ($P = 0.004$), and improvement in their child's appetite/variety of food eaten ($P = 0.004$) (Table 3).

Microcosting

The PHNSP provided supplies, formula, and clinical support to all patients within its catchment area. Costs for the supplies for tube feeding (excluding staffing or other health utilization costs related to tube feeding) was estimated at \$36 766.12 for a year for all 6 patients, (\$6127.69 per patient). If we subtract the cost of Mealttime Support (\$19 840), the total cost savings for the year is

TABLE 1. Patient age, medical history and tube feeding history of Mealttime Support participants

Patient	Age/gender	Medical history	Tube feeding duration
Patient 1	4 y old Male	GERD, oral aversions	NG tube: 4 mo G tube: 7 mo Total duration: 11 mo
Patient 2	4 y 5 mo Female	Ex-30-wk preterm, Trisomy 21, complex congenital heart disease	NG tube since birth G-tube at 21 mo Total duration: 53 mo
Patient 3	3 y 7 mo Female	Congenital diaphragmatic hernia, chronic lung disease, gastroesophageal reflux disease	NG tube since birth G-tube/fundoplication at 3 mo Total duration: 43 mo
Patient 4	18 mo Male	Ex-25-wk preterm, chronic lung disease, gastroesophageal reflux disease	NG tube since birth G-tube/fundoplication at 8 mo Total duration: 18 mo
Patient 5	8 y 2 mo Female	Failure to thrive, recurrent vomiting, congenital heart disease, nephrocalcinosis	NG tube at 3 mo G-tube at 7 mo Total duration: 95 mo
Patient 6	6 y 9 mo Male	Complex congenital heart disease	NG tube since birth G-tube at 9 mo Total duration: 81 mo

TABLE 2. Patient age, medical history and tube feeding history of Mealttime Support participants

Patient	Weight before program start kg (z score)	Height before program start cm (z score)	Weight at 2 wk program end kg (z score)	Weight 9 mo postprogram kg (z score)	Height 9 mo postprogram cm (z score)	Comments on continuation of tube feeds
Patient 1	16 (−0.08)	102.8 (0.14)	15.3 (−0.55)	18.4 (0.23)	107.7 (0.08)	Discontinued all tube feeds × 18 mo postprogram
Patient 2*	13.9 (−1.37)	92 (−2.52)	12.8 (−2.30)	14.4 (−2.85)	93.5 (−3.05)	Discontinued all tube feeding during program
Patient 3	11.8 (−1.45)	92.5 (0.28)	11.7 (−1.65)	12.4 (−1.57)	94.3 (−0.76)	Discontinued all tube feeding during program
Patient 4	9.9 (−0.69)	78 (−1.15)	10.1 (−0.60)	10.8 (−1.44)	85 (−1.46)	Discontinued all tube feeding during program
Patient 5	18.1 (−2.50)	110.5 (−3.24)	17.2 (−3.03)†	N/A†	N/A†	Still tube feeding 4 y postprogram
Patient 6	19.1 (−1.18)	113.6 (−1.19)	18.9 (−1.28)	19.0 (−1.81)	116.5 (−1.30)	Discontinued all tube feeding during program

*Patient has trisomy 21

†Weight recorded at 1 week into program as discontinued program at that time; next available data at 17 mo after program completed: 21.3 kg (−2.24) with height 119 cm (−2.66).

TABLE 3. Survey results pre- and postcompletion of meal time support program

Answers represented by Likert of 1–5 (as indicated)	Mean score preintervention	Mean score postintervention	P
Mealtimes (easy to difficult)	3.6	2.4	0.005
Worried about child’s eating (none to very)	3.6	2.3	0.004
Childs appetite (good to none)	3.4	2.0	0.004
Child gag, spits or vomits (never to most of the time)	3.5	2.3	0.013
Child holds food in mouth without swallowing (never to all the time)	2.9	1.9	0.001
Use of distractions for child to eat (never to most of the time)	2.2	1.7	0.052
Use of force or bribes for child to eat (never to most of the time)	2.8	2.1	0.191
Length of mealtimes (< 10 min to over 40 min)	3.2	3.0	0.443
Worried about child’s weight (none to very)	2.7	3.2	0.177
Child variety of foods (good to very limited)	3.5	1.5	0.002
Influence of feeding on relationship with child (none to very negative)	2.4	1.9	0.096
Influence of feeding on other family relationships (none to very negative)	2.6	2.0	0.051

\$16926 for the 6 patients. Savings would have been higher but 2 patients were on blended tube feeds and received no formula from the program. The cost for Mealtime Support sessions for the child that was discontinued was \$1240. The cost of supplies/formula for

the 5 patients that completed Mealtime Support is \$34281 and if the cost for meal time support is \$18 600, then the total program savings is \$15 681. Only one of the patients in this group was on blended tube feeds.

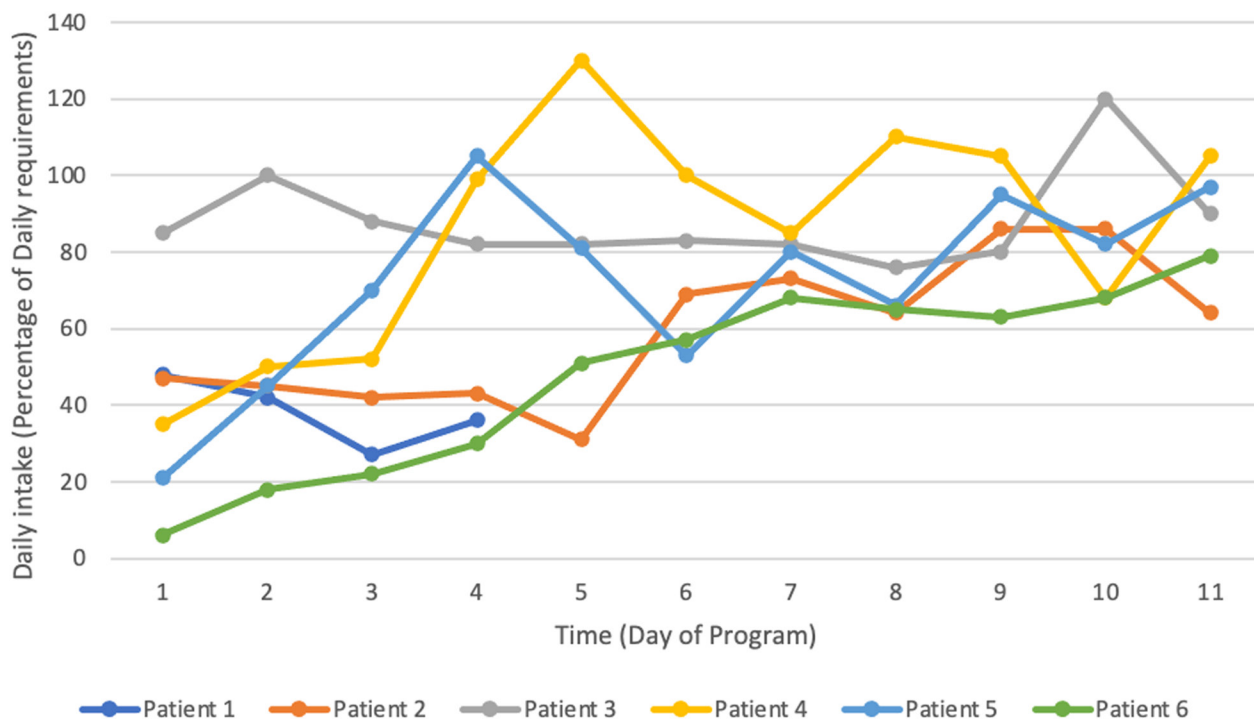


FIGURE 2. Percentage of daily caloric requirements consumed daily during Mealtime Support Program.

The second year of costing showed savings of \$43 471, as we did not have to pay for formula and supplies for 4 patients and there was no cost for the Mealt ime Support sessions. There was some formula and supply costs for 1 patient that did not come right away and for the patient who did not complete the program due to weight loss.

Trends in Pediatric Enteral Nutrition Support in Canada

The CIHI data showed a stable number of pediatric hospital admissions between 2008 and 2019 in Newfoundland (NL), Prince Edward Island (PEI), Nova Scotia (NS), New Brunswick (NB), Ontario (ON), Manitoba (MB), Saskatchewan (SK), British Columbia (BC), and the North West Territories (Terr) with the exception of Alberta (AB), for which pediatric hospital admissions increased from 9856 to 11 738 admissions in 2008 and 2018, respectively.

The number of gastrostomy tube insertions in the provinces over 2008–2019 is shown in the Supplemental Digital Content Figure 1, <http://links.lww.com/PG9/A63>, with apparent increases over time for SK, NS, and AB. PEI and NB were excluded due to low numbers. Using multivariate modeling, individual province (<0.001) and year ($P = 0.018$) independently predict the number of gastrostomy tubes per 100 000 children, explaining in total 36% of the variance for annual gastrostomy tube insertions.

DISCUSSION

Feeding tube dependency has a destructive impact on the quality of life of the children and their families. Tube dependency negatively impacts the parent-child feeding relationship and families often revert to extreme and intrusive measures to encourage their child to eat and drink orally, such as force feeding (19–23). Mealt ime Support was effective in weaning 4/6 children off enteral nutrition support within only a month. Although a labor intensive program, there is a cost benefit that would be cumulative if the children continued to be tube fed over more than an additional year. Importantly, the parents perceived a significant benefit. Although, families were eager to participate in this initiative and encourage their children to eat orally, there was some anxiety related to the aggressive caloric reduction and their child's inability to understand hunger. All of the families had previously tried withholding tube feeds to promote hunger with no success, so there was some emotional distress and apprehension with the hunger based approach. With such a medically complex patient population, families frequently required reassurance and found it challenging to overlook the initial weight loss (24).

Based on the CIHI data, the number of gastrostomy tubes inserted per 100 000 children varied significantly between provinces across the country (Supplemental Digital Content Figure 1, <http://links.lww.com/PG9/A63>). NS, SK, and AB have the highest numbers of gastrostomy tubes inserted with 33, 22, and 22 insertions per 100,000 children in 2018, respectively. These provinces have also seen an increase in the number of tubes inserted over time. There is a growing number of tube dependent children in our own institution and at Mealt ime Support grew to a waitlist of 12 children. However, despite these growing needs and Mealt ime Support's effectiveness and benefit to families demonstrated in the pilot study, the program was not further funded due to a lack of prioritization.

This pilot study's main limitations include the small sample size, the potential for selection bias, and the lack of a control group. It is also difficult to ascertain in this particular cohort of children when they may have stopped tube feeding and therefore interpret the 2-year cost savings for certain. The CIHI data was also not mandated for all facilities for all years across the provinces included and given no individual patient identifiers, multiple tube placements per individual patient cannot be excluded.

CONCLUSIONS

The transition from tube feeding to oral feeding is difficult for children who are tube dependent and poses several economic and psychosocial challenges. Although the number of pediatric hospital admissions have remained stable per 100 000 children in most provinces, except Alberta, there appears to be a growing number of pediatric patients who require feeding tubes in several provinces. Much like successful outpatient hunger provocation programs in the United States (10), Austria (8), the Netherlands (25), and France (26). Mealt ime Support is an effective and cost saving way to wean children off tube feeding. Families reported significant improvements in 8 of 12 mealt ime behaviors and 4/6 children 100% orally fed immediately postprogram completion. A limited microcosting study demonstrates cost-savings over 2 years of approximately \$43 500.00. This promising pilot data sets the stage for future larger scale studies of this type of ambulatory program for children with tube dependency. With a growing number of tubes inserted in children in Canada, there remains a need for multidisciplinary, child, and family-centered, hunger-based outpatient feeding programs to help families achieve safe and adequate oral nutrition and avoid the challenges of tube dependency.

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