

Gastrostomy Tube Weaning and Treatment of Severe Selective Eating in Childhood: Experience in Israel Using an Intensive Three Week Program

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ABSTRACT: **Background:** Children dependent on gastrostomy tube feeding and those with extremely selective eating comprise the most challenging groups of early childhood eating disorders. We established, for the first time in Israel, a 3 week intensive weaning and treatment program for these patients based on the "Graz model."

Objectives: To investigate the Graz model for tube weaning and for treating severe selective eating disorders in one center in Israel.

Methods: Pre-program assessment of patients' suitability to participate was performed 3 months prior to the study, and a treatment goal was set for each patient. The program included a multidisciplinary outpatient or inpatient 3 week treatment course. The major outcome measures were achievement of the target goal of complete or partial tube weaning for those with tube dependency, and expansion of the child's nutritional diversity for those with selective eating.

Results: Thirty-four children, 28 with tube dependency and 6 with selective eating, participated in four programs conducted over 24 months. Their mean age was 4.3 ± 0.37 years. Of all patients, 29 (85%) achieved the target goal (24 who were tube-dependent and 5 selective eaters). One patient was excluded due to aspiration pneumonia. After 6 months follow-up, 24 of 26 available patients (92%) maintained their target or improved.

Conclusions: This intensive 3 week program was highly effective in weaning children with gastrostomy tube dependency and ameliorating severe selective eating. Preliminary evaluation of the family is necessary for completion of the program and achieving the child's personal goal, as are an experienced multidisciplinary team and the appropriate hospital setup, i.e., inpatient or outpatient.

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The provision of adequate calories and essential nutrients is vital for childhood growth and development. Oral intake is ideal, but for children or infants who cannot receive their nutritional requirements orally, nutritional support by enteral or parenteral nutrition is recommended. These patients may need permanent or temporary tube feeding, depending on their medical condition.

Delivery modes of enteral nutrition include nasogastric/duodenal tubes, or, for longer periods, insertion of gastrostomy or jejunostomy tubes [1]. The common indication for enteral nutrition is either medical (e.g., complicated prematurity, neurodevelopment disorders, congenital malformations, metabolic disorders, chromosomal abnormalities), or interactive (e.g., food refusal due to irregular relationship with caregiver, autistic behavior, post-traumatic reaction, food phobia, severe infantile anorexia). More often than not, long-term tube feeding results in tube dependency, defined as more than 3 months of tube feeding, without any medical condition that could interfere with eating or swallowing, and includes active food refusal, tactile and oral oversensitivity, and inability to develop eating skills [2,3]. Factors believed to delay tube weaning include a disrupted normal hunger-satiation cycle, limited experience with oral feeding, development of oral aversion and oral motor dysfunction, parental anxiety, and emotional inability of caregivers to decrease tube feeding [4,5]. Early intervention in tube dependency is essential for successful early weaning. Previous studies have shown that weaning attempts after age 5 years is associated with slow or failed weaning [5,6].

While no treatment approach is universally recognized as effective for tube weaning, a few models have been reported:

- Outpatient clinics with medical or multidisciplinary team consultation allowing slow changes over months or years, in the home environment
- Intensive and short inpatient program with 10–21 days of intensive medical and multidisciplinary supervision. This approach is appropriate for more complex patients or parents with a high degree of anxiety [7-10]
- Short and intensive outpatient program for 3 weeks [9]

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- Weaning program using net coaching, with daily video communications, at home, for 1–2 months [10]
- Rapid home-based weaning with a therapist staying in the family home for 10 days in the natural environment of the child and with the collaboration of local services [11].

Another group of children requiring intervention are those with severe eating disorders. These include highly selective eaters, children with food phobia, or children suffering from post-traumatic stress disorder with psychological stressors. The treatment programs for these patients should include relaxation procedures, systematic food desensitization, gradual introduction of foods, and family therapy [12,13]. Current information concerning this group of eating disorders is scarce. The *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition (DSM V), classifies eating disorders of infancy and early childhood in a new chapter entitled “Avoidant/restrictive food intake disorder: 307.59,” offering a new algorithm for classification. However, this chapter is not detailed enough to guide a therapeutic approach, and the picky eater category was not included [14].

In 2012 the Early Childhood Eating Disorders Unit at Safra Children’s Hospital initiated a tube-weaning intensive program based on the “Graz model” [15-17]. Our unit is a referral center for complex patients, including many with previous failure of weaning in slow outpatient programs. We therefore chose to use the intensive Graz program for tube weaning.

The “Graz model” is based on the principle of establishing self-regulated oral intake. The increase in oral intake is based on the allowance of hunger due to rapid reduction of food intake by tube. The main focus is on the close links between the medical, biosocial and psychodynamic aspects of tube dependency. The program is conducted by a multidisciplinary team that includes pediatricians, a dietician, physical therapists, occupational therapists, a speech therapist, a music therapist, a medical clown, hydrotherapists, and a psychosocial team giving full support to the child and his or her family. We describe here our single-center experience using the Graz model for tube weaning and treating severe selective eating disorders.

PATIENTS AND METHODS

This was a retrospective cohort study of patients who participated in the intensive tube weaning or severe selective eating programs at the Early Childhood Eating Disorders Unit from November 2012 to December 2014. Children with full or partial tube dependency or with severe selective eating were evaluated by the feeding team and clinically assessed 3 months prior to the program. The evaluation included nutritional status, cardiopulmonary problems, the presence of gastro-esophageal reflux disease, metabolic problems, assessment of swallowing (clinical and/or radiological), and a feeding observation. The

principles of the program were explained to the parents. After the initial evaluation, a decision was made regarding inclusion in the program and whether the setting would be on an inpatient or outpatient basis.

INCLUSION CRITERIA

The children had to be in a satisfactory nutritional state and have the necessary oral skills for eating. The families had to express a positive attitude toward participating in the program. Patients with severe unstable underlying disease, suspected aspiration during swallowing, or malnutrition, or whose parents expressed the emotional inability to reduce tube feeding were excluded.

THE GRAZ MODEL

This treatment model is based on intensive (3-4 daily visits per week) inpatient or outpatient treatment for 3 weeks given by a multidisciplinary team and excludes any kind of force feeding. The principle is the establishment of self-regulated oral intake. The increase in oral intake is based on the allowance of hunger by a rapid reduction of food intake by tube. The parents are told not to force-feed their children and are instructed how to recognize and understand their child’s hunger cues. The child can visualize, smell and touch food all day long, but is never told to eat. The contact with food occurs at the child’s will. The main intervention is the promotion of hunger by reducing tube feeding by 50% within 1–3 days in a supervised setting, non-invasive monitoring of the child’s medical condition, and full support of the child’s capacity for autonomous food exploration and self-regulation of intake. Assistance by other disciplines – speech therapy, occupational therapy, physical therapy, music therapy, hydrotherapy, as well as medical clowns – helps to reduce objections, treat abnormal behaviors, decrease oral sensitivity and improve swallowing. Hydrotherapy facilitates relaxing and improving child-parent interaction and communication, and the medical clowns help mainly in lessening objections. Psychosocial support is offered to children and parents. Each day a one hour “play picnic” is held with the children-parents group at noontime. Finger food is presented and touching or playing with it is encouraged without reinforcement. The staff and the parents eat together with the children. The daily schedule of the children is standardized, with four to six individual and group treatment sessions per day. All children receive the same time schedule for treatment with each discipline. A typical schedule is shown in Table 1.

After the program, follow-up is continued weekly for 2–4 weeks, and every 2–4 weeks thereafter depending on the decision of the team and parents.

OUTCOME MEASURES

The primary outcome was weaning from tube feeding and/or independent eating for the tube-dependent patients, and

Table 1. A typical weekly schedule of treatment during the tube-weaning course

	Sunday	Monday	Tuesday	Wednesday	Thursday
08:00-09:00	Swimming pool – Hydrotherapy				
09:00-09:30	Morning picnic with parents group				
09:30-12:00	Medical rounds				
12:00-13:00	Play picnic				
13:00-14:00	Speech therapy	Speech therapy	Music therapy	Speech therapy	Parents group
14:00-15:00	Music therapy	Occupational therapy	Occupational therapy	Music therapy	

Table 2. Demographic and clinical characteristics of the study population

	Tube dependency N=28	Severe selective eating N=6
Age (years)	3.93.1 (0.6–12.6)	6.5 ± 5.7 (2.1–17.6)
Gender (Male:Female)	19:9	5:1
Diagnosis	No. of patients	
Prematurity	3	1
Metabolic syndromes	5	
Congenital hyperinsulinemia	4	
Developmental delay	2	1
Genetic syndromes	10	
Gastrointestinal pathologies	2	
Heart/Lung pathologies	3	
Pervasive developmental disorder		1
Other	3	3 (healthy)

improvement of food variety for the severe selective eaters. The secondary outcome for the former group was a partial response, namely, a reduction of at least 50% in tube feeding.

RESULTS

During the period November 2012 to November 2014, four weaning programs were conducted. The participants were 34 consecutive children: 24 boys and 10 girls aged 4.3 ± 0.37 years (range 0.5–17.5, median 2.8). The patients had been either previously followed at our institution or were referred from other hospitals in Israel where they had failed previous weaning attempts. Twenty-eight children were tube-dependent and 6 were severe selective eaters. Seven were treated as inpatients and 27 as outpatients. The background diseases included metabolic syndromes (glycogen storage disease 1A), congenital hyperinsulinemia, genetic syndromes (cardio-facial-cutaneous, familial dysautonomy, trisomy 21, Costello syndrome, central nervous system neurotransmitter deficiency, Emanuel syndrome, congenital hemophagocytic syndrome, papillomatosis, and unchar-

Table 3. Outcomes in tube-dependent and severe selective eating groups

	Tube dependency (N=28)		Severe selective eating (N=6)
Complete weaning	12	Significant improvement	5
Partial weaning	15	No change	1
Complications	1	Complications	0

acterized), prematurity, developmental delay, gastrointestinal pathologies (hiatus hernia, congenital intestinal obstruction), cardiopulmonary disease (pulmonary hypertension, arterial septal defect), and pervasive developmental disorder. The patient's clinical and demographic characteristics are summarized in Table 2.

The tube-weaning target set for patients with tube dependency was complete weaning for 15 patients and partial weaning for 13. The partial weaning target was set for metabolic conditions, such as persistent hyperinsulinemic hypoglycemia of infancy or glycogen storage diseases, where the goal was complete day weaning but continuous night feeds to avoid hypoglycemia. In order for patients with genetic diseases and a poor prognosis to practice oral and sensory skills, the goal was to reach tasting only.

Of the 28 tube-dependent children, 24 (86%) achieved the target goal, 4 did not reach the desired result, and 1 was excluded during the program due to aspiration pneumonia. No correlation was found between the patient's diagnosis and the weaning outcome. This may be due to the small number of patients in each group, which limited statistical evaluation. Of the six patients with severe selective eating, 5 (84%) achieved a significant improvement in eating and one was unchanged [Table 3]. Follow-up after 6 months was available for 26 patients; 24 (92%) maintained or improved the result achieved in the program.

DISCUSSION

Enteral feeding is an efficient means of nutritional rehabilitation; however, one of the long-term consequences of enteral

feeding is tube dependency. The ideal approach is to prevent tube dependency and to treat it as soon as possible. In our study reported here, 34 patients (28 of them tube-dependent) with complicated baseline diseases were treated intensively in one center according to the Graz model. During the intensive treatment period, 85% of them achieved their target goals: 12 (43%) reached complete weaning and 15 (53%) partial weaning. In addition, we intensively treated six children with severe picky eating, with improvement in 5 (83%).

Several methods for tube weaning are reported in the literature. Outpatient clinics with medical or multidisciplinary teams have the advantage of maintaining a normal routine and low stress level for families, but months to years are usually required to achieve tube weaning and the compliance and success rates are low. Other methods are the inpatient rapid program of 10–21 days and the outpatient 3 week intensive program. These two methods enable rapid and more intense weaning. In both, but especially the inpatient method, there is close medical supervision that allows the inclusion of more complex patients, as well as better cooperation of parents with a high level of anxiety. The success rates of both methods are in the range of 82–90% [7-9]. Most of the described methods relate to case series and there is a lack of comparable study. A recent method using the internet is “net coaching” which takes 1–2 months. This method is more convenient for the patient and family since it is practiced in the patient’s natural environment; it had a high success rate of 92% in one study [10]. Another method reported by Wilken et al. [11] is home-based weaning with a therapist staying in the patient’s home for 10 days and collaborating with the local services. This method was used in 39 patients; their median age was 16 months and the median duration of tube feeding 15 months. The success rate of resuming full oral feeding was 89.7% [11]. The possibility of controlled studies comparing methods is limited due to differences in the patients’ disease severity and baseline characteristics.

A recent review [18] summarized the evidence regarding aspects of tube feeding that are not covered by the ESPGHAN guidelines [19]. Based on the limited available evidence the authors propose the following principles for tube weaning:

- Age and degree of exposure to oral feeding experiences may affect the prognosis for tube weaning
- A multidisciplinary approach is advisable and should ideally involve the collaboration of a pediatric gastroenterologist, psychologist, dietician, occupational therapist, and speech language pathologist
- Behavioral and physical characteristics must be known and should be evaluated before attempting tube weaning, including ability of the child to sit at a table, accept a bite, and adhere to the concept of structured mealtimes
- Diagnosis and treatment of underlying chronic illness are an important part of assessing a child for readiness to wean off tube feedings

- Assessment of the parent-child interaction should be a significant element in treating the tube-fed child.

Multiple non-randomized studies suggest that successful weaning can be achieved with a combination of caloric reduction in tube feedings and behavioral modifications. Our program fulfills these principles. Our experience so far suggests that the preliminary evaluation of the patient, preparation of the family’s expectations, and individual tailoring of treatment with a multidisciplinary team are key factors for successful tube weaning.

Eating-behavioral disorders, including selective eating, are common during early childhood. In some cases, if left untreated, these disorders may result in long-term anorexia, growth disturbance, conduct disorders, food preferences, and macro- or micronutrient deficiencies [20]. A recent review discussed two aspects of selective eating treatment: dietician’s assessment and behavioral therapy [20]. In our intensive program those aspects are addressed and, in addition, relaxation therapies such as hydrotherapy, music therapy, and medical clowns are used to reduce sensory hypersensitivity. In addition, post-traumatic reaction or abnormal family dynamics are treated by the psychosocial team. We treated a small group of six patients who failed previous therapy and the result was a marked improvement in 5 of the 6 (84%).

The limitations of the current study include the small number of patients and the lack of a control method. However, no controlled trials are available, and this is the first report of this type of program in Israel, which achieved similar results to those reported for the Graz method [9,10].

In conclusion, an intensive 3 week multidisciplinary program is highly effective for tube weaning in tube-dependent children and expanding selectivity in those with severe selective eating. Preliminary assessment of the child and the family’s compatibility for the program, and setting of a personal goal for each patient were key factors for success. A prospective study is needed to validate the results.

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