Title Page

Standardized tube weaning in children with long-term feeding-tube dependency: Retrospective analysis of 221 patients

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Abstract:

Objective: This study investigates the outcome of a program specifically designed to establish oral feeding after prolonged tube feeding in children. The necessity for a specific therapeutic intervention was defined by referred clinical impression of a child's suspected ability of being able to learn to eat as suggested by the lack of counteracting medical arguments. At the same time the patients were perceived as having become tube dependant, showing food avoidance and refusing all prior trials of tube weaning by traditional means. The presented intervention is based on supervised reduction of enteral formula within a few days supported by a 3 week program of daily movement-, speech- and occupational therapy, psychoanalytically based eating therapy, psychodynamic coaching and nutritional counselling of the infant and his/her parents.

Patients and Methods: 221 cases were included in this study (age 4 months – 10 years). All patients had been severely ill or were handicapped and had been exclusively fed by tube for most of their life time. The major outcome variable was complete discontinuation of tube feeding with sufficient oral feeding after treatment. This was defined as the child's ability to sustain stable body weight by self motivated oral feeding.

Results: 203/221 patients (92%) were completely and sufficiently fed orally after treatment. Tube feeding was discontinued completely within a mean of 8 days, the mean time of treatment was 21.6 days. 18 children (8%) could not be weaned and remained fully or partially tube fed.

Conclusions: The current method can be used to wean tube-dependent children from prolonged tube feeding by a trained and experienced team. The introduction of oral feeding was possible in most of the referred infants and young children. Tube weaning should be addressed from the beginning of tube feeding in all children who are expected to restore oral feeding. Since successful programs are rare, we have been motivated to present this paper.

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Abbreviations:

PGT: percutaneous gastrostomy tube, NGT: nasogastric tube, GER: gastro-oesophageal reflux, BMI: body mass index, SD: Standard Deviation

1. Introduction

Feeding tubes are used world wide to help children through periods of insufficient weight gain. The rationale for tube feeding is the inability to sustain sufficient weight gain by oral intake, often caused by gastrointestinal pathologies, swallowing problems (dysphagia), the need of highly specialized diets (in metabolic diseases) and any severe medical condition with need for a higher caloric intake (e.g. inborn heart failures).

Since tube dependency in itself is not officially recognized as disorder or complication there is no data addressing the mortality rates of tube fed children available. Nevertheless it has been shown that the mortality of disabled children with long term tube feeding was higher than in the compared population of oral fed handicapped children[25].

The rationale for this retrospective study is to specify a successful tube weaning program in infancy. Many children remain tube dependent after successful healing of their underlying disease. Tube dependency often is accepted as "unintended side-effect" of the treatment. Although the number of tube dependent children is growing all over the world, there is a lack of published literature regarding tube weaning. There are a few case reports[1,2] and behavioural trials centred on tube weaning in handicapped children[3,4,5,6]. Other case reports stress the parental aspect in early food refusal[7,8,9], and new information on the complexity of the development of taste and food preferences[10,11] is available through recent results on flavour programming in childhood. These papers do not specifically deal with tube dependent children.

The population referred for tube weaning is recruited from all fields of paediatric intensive care. No specific diagnosis was found responsible in our sample. The only patients seeking for tube weaning who were not accepted in the program were those with severe dysphagia.

This paper describes the outcome of an standardized tube-weaning program in a population of severely ill and handicapped children. Due to the lack of other reports on tube weaning in infancy, a paper by Benoit[12] was used to compare our concept with an alternative treatment

setting. Benoit showed that nutritional counselling alone cannot support a lasting and positive effect.

Since tube insertion is expected to have an overall positive effect on the nutritional status of the child, associated side effects often are accepted. The reasons for prior tube insertion are addressed in pediatric and surgical literature[13,14,15], and long term complications of tube feeding[16] and home parenteral nutrition (HPN)[17] have been discussed[18,19,20,21,22,23,24.] Of major significance is the fact that tube feeding has been shown to cause an increased mortality rate[25].

In order to decrease mortality of long-term tube-dependent children and increase their life quality by regaining oral autonomy, an effective 3-week program for tube weaning has been developed. The main focus is on the close links between the medical, biosocial and psychodynamic aspects[26] of tube dependency.

2. Methods

Patients

From 1/1/1999 until 12/31/2006 the total of 224 parents requested assistance for weaning their tube fed child (mean age 793.5 days; range 134-2791; SD 552.26). In each case local specialists determined the need for tube weaning. In this period of time, three patients fed by PGT were excluded from the study since introduction of oral feeding was impossible (2 coma patients and 1 with instable glycogen storage disorder). All 221 included patients were investigated and treated according to our specific tube-weaning model. The demographic data of the included children can be seen in Table 1.

All children were treated in the presence of at least one parent or caregiver. Patients' mean gestational birth age was 35 weeks (range 23 – 41, SD 4.98). Seventy-eight patients (35.5%) had been born prematurely between 28 and 37 gestational weeks, forty (18.2%) before 28 weeks of gestation. Sixty-eight (30.9%) patients had been born by Caesarean section, sixteen (14.5%) had been born as one of twins, twelve (5.5%) were one of a triplet birth. The remaining 176 children (80%) were product of single birth.

102 (45.4%) children were admitted with a PGT or Gastro Button, 119 (54.6%) with NGT. 118 (53.6%) were male, 103 (46.4%) female. Age ranged between 4.5 months and 10 years. All children had been fed exclusively by tube for more than 4 months previous to admission (Mean: 650 days; range 121-2700; SD 476.9), most of them for most of their lives. On average, patients had been fed by tube for 83.5% of their lifetime (range 14.4-100; SD 21.91). Previous therapeutic efforts of the 221 patients and their families had included inpatient treatment trials (n=168), outpatient feeding therapy (n=144) and other outpatient weaning trials (n=216). All children had received outpatient speech therapy including oral stimulation in their countries of origin. 69 patients came from Austria, 88 from Germany, 11

from Israel, 5 from Switzerland, 37 from Great Britain, 2 from Croatia and 5 from Denmark, 3 from France, 1 from Algeria. All of them were Caucasian. 19 patients were treated in 1999, 20 in 2000, 27 in 2001, 22 in 2002, 37 in 2003, 18 in 2004, 32 in 2005 and 46 patients in 2006. The mean age at admission was 26.4 months (range 4.5 – 93), mean body mass index (BMI) at admission was 14.47 (range 10.28 – 23.83; SD 2.19). Patient characteristics and the classification of the main medical pathology at admission are presented in Table 1.

Study design

The study was approved by the local ethics commission, and the parents of all patients agreed by written informed consent into the sampling, analysis and publication of the data.

The main hypothesis of the study is: specialized treatment is highly effective and allows weaning severely impaired children even when numerous previous attempts had failed[1]. The primary objective was complete weaning from long-term tube feeding based on sufficient, self-regulated oral intake. Admission into the program in all cases was based on the goal of full oral feeding and tube removal. Birth data was sampled from maternity cards. To achieve homogenous data quality only comparable data was sampled.

Assessment was done by developmentally trained pediatricians and documented according to ZTT: DC 0-3[27,28] including all five diagnostic axes. For the assessment of the relationship disorder (axis 2 ZTT: DC 0-3) various situations were used including an assessment of a feeding trial as an example for a stressful situation and the assessment of a relaxed situation such as unstructured parent-child play. Assessment of quality in parent-infant-relationship was performed according to the recommendations of semi-structured interview (child-working-model-interview by Ch. Zeanah), video analysis of stressful and less stressful parent-child-interaction and the observation of the medical and paramedical team during and around therapeutic sessions. The time of interactive exposure leading to the final score was at least two weeks in most cases. Since two core members of our team were directly involved in the development of the ZTT: DC 0-3[27,28] and translated it into German, the assessment of quality of parent-child-interactions is suspected to be reliable.

Assessment included weight and length, available growth-data, actual feeding history and a team meeting with the child and its family. The classification of the medical condition and handicaps was done using the ICD-10[29] codes on Axis 3 of ZTT: DC 0-3[13]. Medical diagnosis was carried out by pediatricians.

Severity of disease was assessed according to the International Classification of Functioning, Disability and Health (ICF)[30,31] using Part 1 (Impairment of body function and structure) and 2 (Activity limitations and participation restriction). The offered scores in ICF were done by paediatricians, neurological specialists and the parents.

For NGT-fed children, tube weaning was defined by the final and constant removal of the tube. For PGT-fed children, weaning was defined as total cessation of tube feeding. In most PGT-fed children the tube was removed within two weeks after discontinuation of feeds. The end of therapy was defined by discharge. Primary weaning means weaned during inpatient stay. Children for whom weaning was introduced and accomplished at home during aftercare are described as secondarily weaned. No distinction was made between gastrostomy and gastrojejunal tubes. The year of treatment was assigned as the date of discharge. E-mail contact had been established and is continued with all patients.

When determining whether to use BMI versus % ideal body weight BMI was chosen since the calculation is more accurate and ideal body weight charts vary strongly.

Intervention

For better understanding of the following description of the intervention we would like to start with a very brief **case report**:

Chin Lin was referred to our program for tube weaning dependent on nasogastral tube feeding. Chin Lin had been adopted by her American parents from China at the age of 13 months. She had been in care of an orphanage in China after being abandoned and left to be found by her mother. Since Chin Lin was severely malnourished when arriving in the USA she immediately received a NGT and fortunately recovered quite promptly. At the age of 2 years catch-up growth was sufficient and so weaning her from NGT was discussed as necessary goal. It seemed clear to everyone that there were no medical reasons preventing the little girl from learning to eat, but it just did not seem to work.

After one and a half year of unsuccessful trials and feeding programs in Philadelphia, the little girl was referred to our program. Different to the former trials, intervention this time seemed to be organized in a paradoxical way: avoiding all kinds of force-feeding and focusing the interventions to self-awareness, autonomy and motor-skills involved in touching and handling food.

After a brief assessment of one morning in which the child met the therapeutic team, the tube volume was immediately reduced by 40% on day 1, 60% on day 2 and discontinued entirely at the end of the first week (day 6). Daily therapeutic sessions - as presented below - encouraged Chin Lin to touch and play with food, to feed her dolls, her parents and her therapists, gradually resulting in great fun and obvious increase of autonomy and self-assurance in many areas of development. The tube was removed at the end of the first week. Oral intake gradually increased over the following fortnight. After 3 weeks the child could be discharged and returned home. Therapeutic work with the parents included psychological topics like attachment issues, fantasies about the period of time the child had survived in a clearly deprived world and the couple relationship itself. This case describes the

weaning-process in an unusually "healthy" child having suffered "only" from malnutrition. The case also shows that tube feeding served as a highly rewarding and successful intervention for nearly one year thereafter the negative side-effects had become greater than benefit. Most infants referred to our centre have much more complicated medical histories, most of them being survivors of modern neonatal high-tech-medicine.

This weaning program is a multidisciplinary method excluding any kind of force feeding. The method has been presented and published previously[32,33]. The principle of the program is the establishment of self-regulated oral intake. The increase of oral intake is based on the allowance of hunger due to rapid reduction of food intake by tube. Additionally, parents are counselled not to pressure children to eat and are coached to recognize and read their child's hunger cues. The main intervention therefore is the promotion of hunger by reduction of tube feeding within 1 – 3 days in a supervised setting including an intensive, 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.

The presented treatment approach is not behavioural. Neither appetite manipulation nor reinforcement strategies are used. The principles of the program were derived from nondirective play therapy with toddlers and adapted specifically. Since all patients had a history of medical intensive care and/or experiences with repeated exposure to force feeding, all of them showed signs of posttraumatic feeding disorders.

There is no formal structure or routine placed around meals. The only repetitive event is the daily eating therapy session, defined as play picnic. This central therapeutic item consists of a one hour lasting group picnic (7x weekly at noon, 12 am-1 pm) of 3-6 infants and small children in presence of at least one of their parents, who are told only to interfere on strict demand for help of their child. Food is presented at the picnic as finger food buffet in the middle of the room. All food is located on the floor, using plastic dishes. Touching and playing with it is the main goal. Licking, smelling, touching, biting or drinking is not reinforced specifically. The members of the therapeutic weaning team are often present, but in a very unstructured and unpredictable fashion. The team and the parents are told to eat themselves – if they want to. They often are fed by the children. Parents are strictly told not to feed their child. All other contact with food happens in a more or less unstructured manner regulated solely by the cues of the children and the readiness of the staff and family to react appropriately. The child can see, smell and touch food at nearly all times of the day. But it is never told to eat. Every contact with food only happens if the child wants to.

All patients are treated according to the standardized treatment protocol with 4 to 6 individual and group treatment sessions per day[19] (see typical time schedule, Figure 3).

The team supports the parents to review their feeding activities and feeding attempts and helps them to learn to accept a self regulated behaviour of the child within an environment offering food on demand. Speech therapy, occupational therapy, nutritional guidance, psychological counselling and physical therapy are performed on individual needs of the child. Additionally, parents are encouraged to discuss their anxieties and any emotional distress with all members of the team.

One of the greatest challenges is to convince the clinical staff to make organizational changes. Learning to eat can happen only in a clinical environment with a high level of knowledge and expertise about normal eating, feeding development, failure to thrive, starvation, malnutrition and other medical, developmental or psychological conditions associated with food refusal. The core team – paediatricians, nurses and psychologists - offers three medical rounds per day and is available day and night. In some cases a psychiatrist is needed to support the parents[34]. All other members of the medical team are highly trained in the concept of the weaning program. The responsibilities of the team members are as follows:

1. The pediatric team is responsible for coordinating diagnostic and therapeutic units and monitoring the child's medical condition. All pediatricians have additional training in developmental psychology and child psychotherapy. Three pediatricians have specific training in methods of play therapy and attachment theory in infancy. Additional pediatric diagnostic procedure – especially every kind of invasive diagnosis - is permitted only in case of misdiagnosis or emergency.

2. The nursing team is responsible for observing the child and for any intervention to reduce parental stress. In the course of the last decade the nursing team has been trained to perceive the physical and mental health condition of the children and the parents. The team also prepares finger-food trays and appropriate dishes for the daily play picnic and makes food available all day.

3. Eating therapy: The specific invention of the Graz model is the daily play picnic. Based on psychoanalytically oriented play therapy it encourages any kind of self motivated action the infant will present individually and in the group. Any aversive reactions of the children is tried to be prevented. Interference, wiping, cleaning up, force feeding and any kind of harassing, intrusive or constant offering of food is prohibited. Active distraction such as the offering of attractive toys or any reinforcement is also not permitted.

4. Video-analysis is performed to assess and identify intrusive behavior and other specifically maladjusted patterns of child-parent interaction. One parent is usually present at the play picnic, the other one can observe the session through a one-way-mirror. Comments of the parents are identified and positively reframed. This technique reflects video-therapy as described by George Downing[35].

5. Patient deficits in functional emotional development are detected by the developmental psychologist during play sessions using puppets and other creative instruments.

6. Interaction-focused guidance is applied in a task-oriented, unstructured, non directive and undemanding way by all members of the team.

7. Psychoanalytic oriented psychotherapy with the parents is needed to work on traumatic events in the child's and parent's history, offered only if parents ask for additional support. Marital distress is perceived in many cases; often the acknowledgement of prolonged trauma due to the severe illness of the child encourages the parents to assist their child through the weaning and to postpone any required couple-therapy until after the child's treatment.

8. Speech Language Pathologists: Non-traumatic stimulation of the oro-facial area is directed to correct earlier traumatic oral experiences. SLP also offers differentiated diagnosis of dysphagia and other pathologies of swallowing function. The risk of aspiration must be minimized and sometimes requires additional diagnostic procedures.

9. Individual occupational therapy sessions are used to promote tactile mastery, coordination, cognition and sensory integration through stimulation of the vestibular system. All tactile stimulation is done by offering "biological" textures since most tube-fed children are often oversensitive toward tactile stimulation of materials other than plastics.

10. Physiotherapy deals with motor tone and non-constructive feeding patterns. The frequency varies from 3-6 times weekly, and the sessions may include the parents. Parents are encouraged to foster independence. It is common for parents to be overanxious and excessively protective of tube-fed children. Behavioral issues of this kind are frequent topics in the motor-oriented sessions.

11. Nutritional counselling advises the parents in the transition to normal age-appropriate nutrition or special diets if needed. Parents accustomed to tube feeding their child face the challenge of needing to learn about normal food and the specific tastes of their child within a short time-span.

12. Early intervention is helpful for integrating the new situation into everyday life. Organizing an effective team for aftercare is necessary.

Statistical analysis

For the description of the population frequencies, mean values, medians and standard deviations were derived. Time until weaning was defined as the primary outcome variable. All statistical testing was done on a significance level of 5%. To analyze the primary outcome, Kaplan-Meier-estimators were calculated. To find differences between subpopulations, chi square test, log-rank test, and the tests of Breslow and Tarone-Ware were performed. Kaplan-Meier-Estimation was used in order to include the time variable in the analysis and to

enhance comparability[16]. A Cox-model was used to identify independent influencing factors and to estimate the related probability (relative risk) for weaning. All statistical analyses were done with SPSS 14.0 for Windows, version 14.0.1.

3. Results

After treatment, 203/221 (91.8%) patients were weaned completely. Primary weaning within the 3 week inpatient stay was successful in 180 (81.4%) patients. Another 23 children (10.4%) were partially weaned but still needed supplemental feeds at night at the time of discharge; these children were weaned completely during the aftercare phase. The duration from discharge to secondary weaning in these patients was 29.6 weeks in mean (range 3-110, SD 36.6). Eighteen (8.2%) children could not be weaned for specific reasons (Table 2). None of the weaned children relapsed to tube feeding after the program and during the aftercare phase of 16 months.

Figure 1 illustrates the time until discontinuation of the tube for primary-weaned children. Tube feeding was stopped completely within 8 days (range 0 – 39) in 50% of patients. The mean time of inpatient treatment was 21.6 days (range 2-52, SD 9.97). During inpatient treatment there was an average weight loss of 4.32% (range 0-14.25; SD 3.88). Children with PGT needed slightly longer to be weaned (log-rank n.s.; Breslow 0.044; Tarone-Ware 0.043) than those with NGT.

A comparison of underlying medical diagnosis (Figure 4) showed no significant differences between the main groups. However, children with cardiac problems were weaned significantly faster[36] than the others. Patients with inborn errors of metabolism required the longest time for weaning and made up the majority of secondary weaned children (8/12).

A comparison of the severity and duration of inpatient treatment shows significant differences (Figure 2). The mean time of weaning increased in relation to the grade of severity (Log-Rank 0.006; Breslow 0.32; Tarone-Ware 0.15) from 18 days in less severely disabled children up to 26 days in children with the most severe illnesses.

Table 3 presents the Cox-model for significance and chance (relative risk) for successful tube weaning. Our sample shows that the chance for successful weaning increases the earlier in the treatment program the tube is removed. A higher BMI at admission prolongs the time needed for weaning. An increase in the severity of disease also decreases the chance for weaning. The results suggest an inverse correlation between gestational age and chance for successful weaning; preterm born children can be weaned more easily.

Parameters that do not appear to influence weaning time and outcome are: sex, sub-type of feeding disorder[37,38,39], sub-type of interaction classification between parents and child, degree of functional-emotional developmental delay and the occurrence of birth by Caesarean section. Developmentally delayed children could be weaned as well as others.

Surprisingly, our data indicate that the quality of interaction between children and parents surprisingly does not significantly influence the weaning-outcome.

4. Discussion

Results

The results of this study indicate that weaning of tube-dependent children from nutritional tubes was successful in 91.8% of the patients. In contrast to other methods, this program shows the highest rate of success. It can also be used in severely ill children.

Patients with inborn metabolic disorders needed the most time to be weaned and made up the majority of secondary-weaned children. This may be caused by the inability to provoke hunger due to the contraindication of starvation due to the underlying metabolic disease. Children with the most severe illnesses needed the longest time to be weaned, based on the fact that these multi-morbid children could be discharged only after regaining full stabilization. Children with congenital heart diseases were weaned fastest. This may be due to over-nutrition[19] to gain weight prior to surgery and the children's better tolerance for short-term starvation.

The study showed that a higher BMI at admission increases the time needed for weaning. Most of theses children were older at admission and had a longer history of tube feeding. We believe that the longer duration of tube feeding can be seen as a more severe kind of tube dependency that prolongs the time needed for weaning. Maybe children with a higher BMI need longer time for weaning because they have more fat-mass (which has not been measured within this study) and so they have less hunger than those with very low BMI – based on the regulation of hunger by adipozytokines.

Every child included in this study had undergone prior failed attempts of weaning. Most had been hospitalized for long periods and many of them showed the full range of post-traumatic feeding disorders[40] with panic attacks (46%), total food refusal (69%) or high levels of anxiety (42%). Nearly all the infants treated met the specific criteria of post-traumatic feeding disorder. Additionally some children showed co-morbidity with the subtype of neuro-sensory impairment; other children showed co-morbid symptoms of attachment or individuation disorder.

All patients who were weaned have remained orally fed. Two children suffered from primary dwarfism: their growth remained sub-normal, but within the range of expectation for their specific diagnosis. All parents reported an overall improvement in various developmental levels, such as speech development, motor and social skills. We have not been able to verify or categorize these reports since the sampling of data did not follow a clear study design. In all cases the mean BMI after 3 and 16 months was higher than in the period of exclusive tube feeding prior to admission.

Intervention

Other methods to introduce oral feeding have been based mainly on behavioral treatment using flooding-procedures[41,42]. One model, derived from the Graz model, allows less severely disabled children to be weaned in a home-based setting[43]. Premature born neonates have been weaned using oro-pharyngeal stimulation techniques[44,45]. Little is known about the general outcome of tube feeding in infancy.

Since most of the children in our study were severely ill and needed intensive pediatric monitoring during therapy, the presented method had to be applied in an inpatient setting. Additionally, the large geographical area serviced made an outpatient setting impossible for most of the patients.

In this study the treatment was evaluated in its entirety without examining the relative importance of individual modules. Clearly the method influences the child's progress in the developmental task of learning to eat just as much as the specific suitability and fitness of the therapist's personality with the child and family. Because the various therapies are intermingled and cannot be clearly separated, the treatment program is essentially holistic. Each member of the team works independently, and clinical impressions are shared weekly.

The most important point of the model is the concept of full oral autonomy of the infant from birth and the implementation of this concept into the daily handling of parents and caregivers dealing with eating disorders, feeding disorders and tube-fed infants. Hunger is the main motivation for the attainment of self-regulated eating behavior.

The term "post-traumatic" as defined by Irene Chatoor[40] focuses on experiences of direct oral traumatisation - mostly single or repeated events of choking or gagging. Another interpretation of the term post-traumatic is to focus on the existence of a retrograde mental trauma caused by chronic deprivation from the loving care taker or repeated and dramatic scenes of separation during long hospital admissions. In the classification as used in our program which has been adapted from Chatoor´s work on feeding disorders in the 1980s we define post traumatic feeding disorder as shown by the existence of explicit food refusal, food avoidance, turning away the head when food is presented, mostly combined by tactile hypersensitivity, disgust and the unwillness to even touch food. Nearly 90% of our the population of tube dependent children spent their first weeks in live on intensive-care-units thus repeatedly being exposed to suction, oral mechanical traumatisation and experiences of repeated aspirations.

Conclusion

Since it has been shown that tube feeding is associated with troubling side effects and increased mortality rates in children[26], weaning should be the main goal in treatment.

The present treatment costs $864 (USD) per day when applied as inpatient therapy and the total inpatient treatment cost is approximately $18,000 (USD). The program when applied as outpatient costs 10% of the presented fees. The number of children treated in the inpatient setting was equal to the number of children treated as outpatients, even though the monthly groups varied in size from 2-8 infants/group and their chosen kind of setting.

The economic and psychological costs caused by gastrostomy tube feeding are estimated to be $37,232 (USD) per year[46]. Hospital costs for treatment of associated complications increase the annual cost of gastronomy tube feeding.   The three-week inpatient tube weaning program is therefore economically justified and reduces a burden on healthcare systems. Additionally, our inpatient program allows weaning severely ill children for whom outpatient weaning would not be possible. Fully randomized trials in tube weaning are practically impossible because parents insist on weaning their child as early and as quickly as possible. Any attempt to divide the population into two groups, of which only one received treatment can be dismissed on ethical grounds. Nevertheless, as Benoit[13] has pointed out, different therapy protocols can be used. The introduction of oral feeding improves the quality of life[47,48,] leads to very positive general developmental changes and reduces the rate of complications[49].

The field of tube feeding is not well investigated and the overall success of tube feeding has not yet been shown in reviews, with the exception of tube-fed children with cerebral palsy[50].

In conclusion, as other authors have also suggested, weaning should be the primary goal in treating those tube-fed children[51] who are candidates for selective and short-term tube feeding. We believe that weaning is possible in most children lacking severe cerebral dysfunction with severe dysphagia. Questions regarding the indication of tube feeding, the recommendation of duration of tube feeding, the nutritional aspects of prior tube feeding and during the tube weaning phase, food preferences during the transition from tube to oral feeding and aftercare are not addressed in this study. Further investigations are needed to develop clear criteria for these questions. Since 2007 – due to increase of referrals (71 within the first 9 month of 2007) - we have changed the presented inpatient model to a mainly outpatient one and have introduced a computerized data collection method, of which we hope to present further interesting details in the near future.

model for children not needing an inpatient setting. We also thank all our colleagues in Graz, Vienna, Salzburg, Israel, Zürich, Toronto, Berlin and many more centres for their trust in referring "unweanable" patients and their constant positive reinforcement and interest in the presented weaning method. *We also thank A. Linzbichler (Department of Child Radiology Graz), E. Kerschischnik (Physiotherapy), M. Knappitsch (SLP), Chr. A. Hauer (Division of Gastroenterology), U. Sechser (Department of Nutritional Sciences), M. Höllwarth and A. Huber (University Hospital for Child Surgery Graz) for their constant support in diagnostics and treatment of this large group of specifically referred patients from abroad. We also thank J.Wittenberg (Hospital of Sick Children, Toronto), Julie Menella (Monell Centre of senses), Philadelphia, A. Levine and Y. Roth (Wolfson Medical Centre, Holon, Israel), M. Keren (Geha Medical Centre, Tel Aviv, Israel) for their cooperation in the treatment of the Israeli patients. Special thanks to E. Kvas (Hermesoft, Graz, Austria) for bio-statistical counselling. This study was partially supported by grants from the Styrian Government (Austria), department for science and research. The Graz model has been issue of a professional film documentation "the child that never ate" broadcasted by VGOODFilms, U.K. in 2006.*

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