
INPATIENT TUBE WEANING IN CHILDREN WITH LONG-TERM FEEDING TUBE DEPENDENCY: A RETROSPECTIVE ANALYSIS

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ABSTRACT: This study investigates the outcome of an intervention program to establish oral feeding after prolonged tube feeding in children. The intervention is based on supervised reduction of enteral formula within a few days supported by a 3-week program of speech therapy, occupational therapy, psychoanalytically based eating therapy, physical therapy, psychodynamic coaching, and nutritional counseling of the infant and his or her parents. Two hundred twenty-one cases were included in this study. All patients had been severely ill or were handicapped and had been exclusively fed by tube for most of their lives. The major outcome variable was complete discontinuation of tube feeding with sufficient oral feeding after treatment, defined as the child's ability to sustain stable body weight by self-motivated oral feeding. Two hundred three patients (92%) were completely fed orally after treatment. Tube feeding was discontinued completely within 8 days in mean, and mean in-patient treatment time was 21.6 days. The current method can be used by a trained and experienced team to wean tube-dependent children from prolonged tube

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feeding. Tube weaning should be addressed from the beginning of tube feeding in all children who are expected to restore oral feeding after the phase of nutritional stabilization. Since successful programs are rare, we were motivated to present our results of this elaborate program in this article.

RESUMEN: Este estudio investiga el resultado de un programa de intervención para establecer en los niños la alimentación bucal después de una prolongada alimentación por tubos. La intervención está basada en una supervisada reducción de fórmula entérica dentro de pocos días, apoyada en un programa de 3 días de terapia del habla, terapia ocupacional, terapia de alimentación basada en el psicoanálisis, terapia física, entrenamiento sicodinámico y consejos nutricionales para el infante y sus padres. En este estudio se incluyen 221 casos. Todos los pacientes habían estado severamente enfermos o se habían incapacitado y habían sido alimentados exclusivamente por medio de tubos durante la mayor parte de sus vidas. La variable de resultado más fuerte fue la completa discontinuación de la alimentación por tubos con suficiente alimentación bucal después del tratamiento, definida como la habilidad del niño para sostener el peso estable del cuerpo por medio de alimentación bucal automotivada. Después del tratamiento, 203 pacientes (92%) fueron completamente alimentados bucalmente. La alimentación por tubos fue descontinuada completamente dentro de un promedio de 8 días, y el promedio en cuanto al tratamiento del paciente fue de 21.6 días. El actual método puede ser usado por un equipo entrenado y experimentado para apartar a los niños dependientes del tubo de una prolongada alimentación por tubos. La separación del tubo debe ser explicada desde el principio a todos los niños cuando existen las expectativas de restaurar la alimentación bucal después de la fase de estabilización nutricional. Ya que los programas exitosos son raros, se nos ha animado a presentar los resultados de nuestro elaborado programa en este artículo.

RÉSUMÉ: Cette étude a porté sur le résultat d'un programme d'intervention pour établir une prise orale de nourriture après une alimentation par sonde prolongée chez les enfants. Cette intervention est basée sur une réduction supervisée de formule de nutrition entérale après quelques jours, avec le soutien d'un programme d'orthophonie de trois semaines, combiné avec une kinésithérapie, une thérapie psychanalytique portant sur la prise de nourriture, un soutien psychodynamique avec un coach et des conseils nutritionnels pour le bébé et ses parents. 221 cas ont été inclus dans cette étude. Tous les patients avaient été sévèrement malades ou étaient handicapés et avaient été exclusivement nourris par sonde pendant la plupart de leur vie. Le résultat variable le plus important était la discontinuation totale de l'alimentation par sonde avec une prise orale de nourriture suffisante, définie par la capacité de l'enfant à soutenir un poids du corps stable par une prise de nourriture auto-motivée. 203 patients (92%) se sont avérés totalement nourris oralement après le traitement. L'alimentation par sonde fut totalement discontinuée après 8 jours en moyenne, et la moyenne du traitement en hospitalisation était de 21,6 jours. La méthode actuelle peut être utilisée par une équipe formée et expérimentée afin de sevrer de la prise de nourriture prolongé par sonde les enfants qui dépendent d'une alimentation par sonde. Le sevrage de la sonde doit être abordé dès le début de l'alimentation par sonde chez tous les enfants chez qui on espère restaurer la prise orale de nourriture après une phase de stabilisation nutritionnelle. Nous avons été d'autant plus motivés à présenter les résultats de ce programme élaboré que les programmes qui réussissent sont rares.

ZUSAMMENFASSUNG: Die vorliegende Studie untersucht die Ergebnisse eines Behandlungsmodells zur (Wieder-) Aufnahme oraler Ernährung nach protrahierter Sondenernährung bei Kindern. Die Behandlung besteht aus der medizinisch supervidierten Reduktion der enteralen Ernährung innerhalb von wenigen Tagen und einer 3 Wochen andauernden interdisziplinären Behandlung mit Physiotherapie, Logopädie, Ergotherapie, einer psychoanalytisch basierten Esstherapie sowie Coaching und psychodynamischer Ernährungsberatung des Kindes und seiner Eltern. 221 Fälle wurden in die Studie eingeschlossen.

Alle Patienten waren schwer krank und/oder behindert und wurden den größten Teil ihres Lebens ausschließlich über Nahrungssonden ernährt. Als Erfolgskriterien wurden definiert: Vollständige Entwöhnung der Sondenernährung bei ausreichend oraler Nahrungsaufnahme nach dem Ende der Behandlung und die Fähigkeit des Kindes, ein stabiles Körpergewicht bei einer von Eigeninteresse geleiteten oralen Nahrungsaufnahme aufrecht zu erhalten. 203 Patienten (92%) konnten sich nach der Behandlung vollständig oral ernähren. Im Median konnte die enterale Ernährung innerhalb von 8 Tagen beendet werden, bei durchschnittlich 21,6 Tagen stationärer Behandlung. Die vorgestellte Behandlungsmethode kann durch ein geschultes und erfahrenes Team verwendet werden, um sondenernährte Kinder nach längerer enteraler Ernährung von der Sonde zu entwöhnen. Die Entwöhnung von der Sonde sollte bereits vor Beginn einer Sondenlegung bei allen Kindern thematisiert werden, die nach einer Phase der Gewichtstabilisierung voraussichtlich wieder oral ernährt werden können. Da erfolgreiche Programme zur Sondenentwöhnung selten sind, ist es uns besonders wichtig, die Ergebnisse der aufwendigen Behandlungsmethode in diesem Journal zu präsentieren.

抄録：この研究は、子どもにおいて長期にわたる経管栄養の後に経口摂取を確立するための介入プログラムの結果を調査する。介入は、監督を受けながら経腸栄養剤を数日以内に減量する方法に基づき、乳児と親に対する3週間のプログラムである言語療法、作業療法、精神分析に基づく食事療法、理学療法、精神力動的なコーチングおよび栄養カウンセリングによって、支援されている。221ケースがこの研究に含まれた。すべての患者は重篤な疾患あるいはハンディキャップがあり、人生の大部分管を通してのみ栄養摂取してきた。主要な結果の変数は、治療後の十分な経口摂取を伴う完全な経管栄養の中止であり、それは自発的な経口摂取により安定した体重を維持できる子どもの能力として定義された。203人の患者(92%)が治療後に完全に経口摂取した。経管栄養は、平均8日以内に完全に中止された。そして平均の入院治療日数は21.6日だった。現在の方法は、管に依存した子どもが長期化した経管栄養から離脱するための訓練を受け、経験を積んだチームにより使用されることができる。経管栄養からの離脱は、栄養的に安定した時期の後に経口摂取を回復できると期待されるすべての子どもに、経管栄養の始めから取り組まれるべきである。成功したプログラムはまれなので、われわれはこの精緻なプログラムの結果をこの論文で提示したいと動機付けられた。

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Feeding tubes are used world-wide to help children through periods of impaired oral intake and 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 a disorder nor has been reported as common complication of long-term tube feeding, there are no available data addressing the epidemiology or mortality rates of tube-fed children. Nevertheless, it has been shown by Strauss, Kastner, Ashwal, and White (1997) that the mortality of disabled children with long-term tube feeding is higher than that in the compared population of oral-fed handicapped children. In this article, the relative risk of mortality associated with tube feeding is 2:1, and the tube-fed children show a significantly higher mortality rate. Children with less severe disabilities especially show a doubled mortality rate in comparison to handicapped children fed orally.

Many children remain tube dependent after successful healing of their underlying disease. Tube dependency often is accepted as an unintended side effect of the treatment. Although the number of tube-dependent children has been growing all over the world, there is a lack of published literature regarding tube weaning. There are a few case reports (Burmucic, Trabi,

Deutschmann, Scheer, & Dunitz-Scheer, 2006; Hoch, Babbitt, Coe, Krell, & Hackbert, 1994) and behavioral trials centered on tube weaning in handicapped children (Ahearn, Castine, Nault, & Green, 2001; Riordan, Iwata, Finney, Wohl, & Stanley, 1984; Sullivan, Thomas, & Eltumi, 2002; Werle, Murphy, & Budd, 1993). Other case reports have stressed the parental aspect in early food refusal (Evans, Thorne, Taufiq, & George, 2006; Jotzo & Poets, 2005; Luisella, Medeiros, Jasinowski, Smith, & Cameron, 1994), and new information on the complexity of the development of taste and food preferences (Gerrish, & Menella, 2001; Handen, Mandell, & Russo, 1986) is available through recent results on flavor programming in childhood. These studies did not specifically deal with tube-dependent children.

The rationale for this retrospective study is to report the results of a successful tube-weaning program in infancy. The population referred for tube weaning to our program was recruited from all fields of pediatric intensive care. No specific diagnosis was found responsible in our sample. The only patients seeking tube weaning who were not accepted in the program were those with reported severe dysphagia.

This article describes the outcome of an inpatient tube-weaning program in a population of severely ill and handicapped children. Due to the lack of other reports on tube weaning in infancy, an article by Benoit and Coolbear (1998) was used to compare our concept with an alternative treatment setting. Benoit and Coolbear showed that nutritional counseling 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 have been addressed in the pediatric and surgical literature (Blackman, & Nelson, 1985; McHattie, 2005; Rempel, Colwell, & Nelson, 1998), and long-term complications of tube feeding (McMahon, Hurley, Kammath, & Mueller, 2005) and home parenteral nutrition (Cavicchi, Beau, & Crenn, 2000) have been discussed (Bufler, Ehringhaus, & Koletzko, 2001; Colomb, Fabeiro, & Dabbas, 2000; Dunitz et al., 1996; Fulhan, Collier, & Duggan, 2003; Heine, Reddihough, & Catto-Smith, 1995; Mason, Harris, & Blissett, 2005; McGrath, Splaingard, Alba, Kaufman, & Glicklick, 1992). Of major significance is the fact that tube feeding has been shown to cause an increased mortality rate (Strauss et al., 1997).

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 of tube dependency (Dunitz-Scheer et al., 2001).

METHOD

Patients

From January 1, 1999 until December 31, 2006, a total of 224 parents requested assistance for weaning their exclusively tube-fed child (M age = 793.5 days, range = 134–2,791, SD = 552.26). In each case, local specialists determined the need for tube weaning. In this time period, 3 patients (2 coma patients and 1 with instable glycogen storage disorder) fed by percutaneous gastrostomy tube (PGT) were excluded from the study since introduction of oral feeding was impossible. All 221 included patients were investigated and treated according to our specific tube-weaning model. Table 1 presents the demographic data of the included children.

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%)

were born prematurely between 28 and 37 gestational weeks, 40 (18.2%) before 28 weeks of gestation. Sixty-eight (30.9%) patients had been born by Cesarean section, 16 (14.5%) had a twin, 12 (5.5%) were one of a triplet birth. The remaining 176 children (80%) were products of a single birth.

One hundred two (45.4%) children were admitted with a PGT or Gastro Button, 119 (54.6%) with a nasogastric tube (NGT). One hundred eighteen (53.6%) were male, and 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 ($M = 650$ days, range = 121–2,700, $SD = 476.9$), many 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 weaning 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. Sixty-nine patients came from Austria, 88 from Germany, 11 from Israel, 5 from Switzerland, 37 from Great Britain, 2 from Croatia, 5 from Denmark, 3 from France, and 1 from Algeria. All of them were Caucasian. Nineteen 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 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.

TABLE 1. Characteristics of Patients and Classification of Main Pathology

	<i>n</i>	%	
No. of patients included	221	100	
Male	118	53.4	
Female	103	46.6	
Type of tube			
PGT	102	46.2	
NGT	119	53.8	
	<i>M</i>	<i>range</i>	<i>SD</i>
Age at admission (days)	791.13	134–2,791	552
Weight at admission (kg)	9.76	3.92–23.5	3.84
Gestational age at birth (weeks)	35.07	23–41	4.98
Duration of tube feeding before weaning (days)	650.75	60–2,700	476.87
Duration of tube feeding (% of lifetime)	83.5	14.4–100	21.91
Group of main pathology	<i>n</i>	%	
Complicated prematurity	48	21.7	
Congenital malformation of the heart	41	18.6	
Congenital metabolic disease	54	24.4	
Malformation or disease of the gut	46	20.8	
Neurological diseases	18	8.2	
Psychiatric disease of child or parents	12	5.4	
Healthy, no diagnosis on Axis 3 of ZTT	2	0.9	

Note. PGT: percutaneous gastrostomy tube; NGT: naso-gastral tube; ZTT = ZERO TO THREE.

Study Design

The study was approved by the ethics commission of the Medical University Graz, and the parents of all patients agreed by written informed consent to the sampling, analysis, and publication of the data.

The main hypothesis of the study was that specialized inpatient treatment is highly effective and allows weaning severely impaired children even when numerous previous attempts have failed (Hoch et al., 1994). The primary objective was complete weaning from long-term tube feeding based on sufficient, self-regulated oral intake. Admission in all cases was based on the goal of full oral feeding and tube removal.

Birth data were sampled from maternity cards. To achieve homogenous data quality, only comparable data were sampled.

Assessment was done by developmentally trained pediatricians and documented according to ZTT: DC 0–3 (McMahon et al., 2005; ZERO TO THREE, 1994), 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 the parent–infant relationship was performed according to the recommendations of the semistructured interview (child-working-model interview, Zeanah & Zeanah, 1989), video analysis of stressful and less stressful parent–child interactions, and observation of the medical and paramedical teams during and around therapeutic sessions. Time of interactive exposure leading to the final score was at least 2 weeks in most cases. Since two core members of our team were directly involved as task-force members in the development of the ZTT: DC 0–3 and translated it into German, assessment of the 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 his or her family. The classification of the medical condition and handicaps was done using the ICD-10 (World Health Organization, 2001) codes on Axis 3 of ZTT: DC 0–3. Medical diagnosis was carried out by pediatricians.

Severity of disease was assessed according to the International Classification of Functioning, Disability and Health (ICF; Simeonsson et al., 2003; World Health Organization, 2001) using Parts 1 (Impairment of body function and structure) and 2 (Activity limitations and participation restriction). The offered scores in ICF were done by pediatricians, 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 2 weeks after discontinuation of feeds. 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 was established and continued with all patients until 2009.

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

INTERVENTION

For a clearer understanding of the following description of the intervention, we begin with a brief case report.

Chin Lin

Chin Lin was referred to our program at the age of $3\frac{7}{12}$ years for tube weaning dependent on NGT feeding. Chin Lin had been adopted by her American parents from China at the age of 13 months. She had been cared for in an orphanage in China after being abandoned and left to be found. Since Chin Lin—unlike the other little girls in the orphanage—was reported to show food avoidance and refusal of nearly all feeding attempts, she was severely malnourished when arriving in the United States, and she immediately received an NGT and fortunately recovered quite promptly. At 2 years of age, catch-up growth was sufficient, and so weaning her from NGT was discussed as a necessary goal. It seemed clear to everyone that there were no medical reasons preventing the Chin Lin from learning to eat, but it just did not seem to work.

After $1\frac{1}{2}$ years of unsuccessful trials and feeding programs in and around Philadelphia, the little girl was referred to our program. Intervention this time was organized in a different way: avoiding all kinds of force-feeding and focusing the interventions to self-awareness, autonomy, and self-motivated motor skills involved in touching and handling food.

After a brief assessment 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 (presented later) 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. Food was repeatedly around the child at nearly all times. Two daily tub baths in warm water with no soap and swimming in the hospital pool encouraged tactile experiences involving water. 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 such as attachment issues, fantasies about the period of time when the child had survived in a clearly deprived world, and the couple's relationship itself.

This case describes the weaning process in an unusually "healthy" child having suffered "only" from failure to thrive by food refusal. The case also shows that tube feeding served as a highly rewarding and successful intervention for nearly 1 year. Thereafter, negative side effects had become greater than the benefits. In contrast to this case, most infants referred to our center 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 (Dunitz-Scheer et al., 2001; Trabi, Dunitz-Scheer, & Scheer, 2006a). 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 counseled 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 to 3 days in a supervised setting, including an intensive, noninvasive monitoring of the child's

Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday		
8–9	Ward round (daily)								
9–10	PhT	OT	SLP	PhT	SLP	Free for family activities			
10–11		PhT		Staff					
11–12	SLP		OT	Conference	PhT				
12–1	Play picnic (daily)								
1–2	Psy			PTDev	Nutr				
2–3	Ward round (daily)								
3–4	Nutr	PTP			OT				
evening	Family time								

PhT = physiotherapy; OT = occupational therapy; SLP = speech language pathology therapy; PTP = psychotherapy for parents; PTDev = developmental oriented psychotherapy; Psy = psychology therapy item; Nutr = nutritional counseling.

FIGURE 1. Typical time schedule. Time and frequency of therapy items vary from one child to another.

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 behavioral. Neither appetite manipulation nor reinforcement strategies are used. The principles of the program were derived from nondirective play therapy with toddlers and adapted specifically for this population. 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 1-hr group picnic (seven times weekly at noon to 1 p.m.) of 3 to 6 infants and small children in the presence of at least one of their parents, who are told only to interfere on strict demand for help by their child. Food is presented at the picnic as a 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. 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—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 cues from 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 is never told to eat. Every contact with food happens only if the child wants to.

All patients are treated according to the standardized treatment protocol with four to six individual- and group-treatment sessions per day (Dunitz-Scheer et al., 2001) (see typical time schedule, Figure 1).

The team supports the parents to review their feeding activities and feeding attempts, and helps them to learn to accept self-regulated behavior of the child within an environment offering food on demand. Speech therapy, occupational therapy, nutritional guidance, psychological counseling, and physical therapy are performed according to the individual needs of the child. In addition, 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—pediatricians, nurses, and psychologists—offers three rounds per day and is available day and night. In some cases, a psychiatrist is needed to support the parents (Dunitz et al., 1996). All other members of the medical team are highly trained on the concepts of the weaning program. Responsibilities of the team members are as follows:

- The pediatric team is responsible for coordinating diagnostic and therapeutic sessions 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.
- 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.
- *Eating therapy*: The specific invention of the Graz Model is the daily play picnic defined as “Spieleessen.” Based on psychoanalytically oriented play therapy, it encourages any kind of self-motivated action the infant will present individually and in the group. The team tries to prevent any aversive reactions of the children. Interference, wiping, cleaning up, force feeding, and any kind of harassing, intrusive, or constant offering of food are prohibited. Active distraction, such as the offering of attractive toys or any reinforcement, also is not permitted.
- 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 parent 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 Reck, Weiss, Fuchs, Downing, and Mundt (2004).
- Patient deficits in functional emotional development are detected by the developmental psychologist during play sessions using puppets and other creative instruments.
- Interaction-focused guidance is applied in a task-oriented, unstructured, nondirective, and undemanding way by all team members.
- Psychoanalytic-oriented psychotherapy with the parents is needed to work on traumatic events in the children’s and parents’ 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 couples therapy until after the child’s treatment.
- *Speech Language Pathologists*: Nontraumatic stimulation of the orofacial area is directed to correct earlier traumatic oral experiences. They also offer differentiated diagnosis of

dysphagia and other pathologies of the swallowing function. The risk of aspiration must be minimized and sometimes requires additional diagnostic procedures.

- 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.
- Physical therapy deals with motor tone and nonconstructive feeding patterns. The frequency varies from three to six 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.
- Nutritional counseling 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.
- 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, *Mdns* and *SDs* 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 to include the time variable in the analysis and to enhance comparability. A Cox Model was used to identify independent influencing factors and to estimate the related probability (i.e., relative risk) for weaning. All statistical analyses were done with SPSS 14.0 for Windows, Version 14.0.1.

RESULTS

After treatment, 203 of 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. 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 (see Table 2). None of the weaned children relapsed to tube feeding after the program or during the aftercare phase of 16 months.

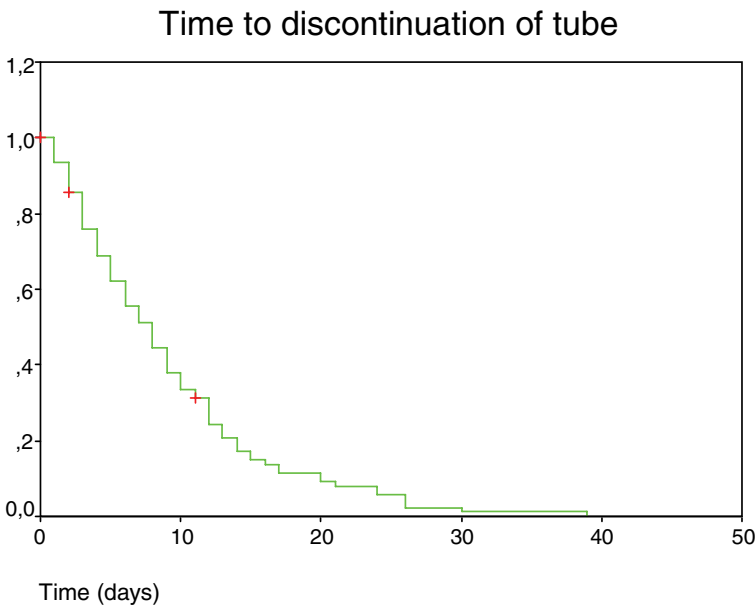
Figure 2 illustrates the time until discontinuation of the tube for primary-weaned children. Tube feeding was stopped completely within 8 days (range = 0–39) in 50% of patients. The mean time of inpatient treatment was 21.6 days (range = 2–52, *SD* = 9.97). During inpatient treatment, there was an average weight loss of 4.32% of body weight at admission (in kg) (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 did those with NGT.

TABLE 2. Causes for Not Weaning 18 Children

Case	Cause for Impracticality of the Weaning Protocol
1	Chromosome defect, trisomy 18, severe disorder, died at home
2	Parents decided to drop out of the protocol due to acute infection
3	Citrullinemia, partially weaned, tube feeding only during sleep
4	Persisting neonatal hyperinsulinism, partially weaned, tube feeding during sleep
5–9	Severe dysphagia, recurrent aspirations, and pneumonias, change from NGT to PGT
10	Down syndrome, trisomy 21, malnutrition, partially weaned, night feeds kept
11, 12	Esophageal atresia, severe psychological dependency, partially weaned
13	Francescetti syndrome, Choanalatresia, insufficient oral intake
14	Diagnosis of an astrocytoma, transferred to oncology unit
15, 16	Infantile larynx, tracheomalacy, tracheostoma, night feeds kept
17, 18	Subtotal stenosis of esophagus, transferred to surgical department for operation

A comparison of underlying medical diagnosis (Figure 3) showed no significant differences between the main groups; however, children with cardiac problems were weaned significantly faster (Trabi, Dunitz-Scheer, & Scheer, 2006b) than were the others. Patients with inborn errors of metabolism required the longest time for weaning and made up the majority of secondary-weaned children ($n = 16$ of 23).

A comparison of the severity and duration of inpatient treatment shows significant differences (Figure 4). 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.

**FIGURE 2.** Time to discontinuation of tube (Kaplan–Meier chart).

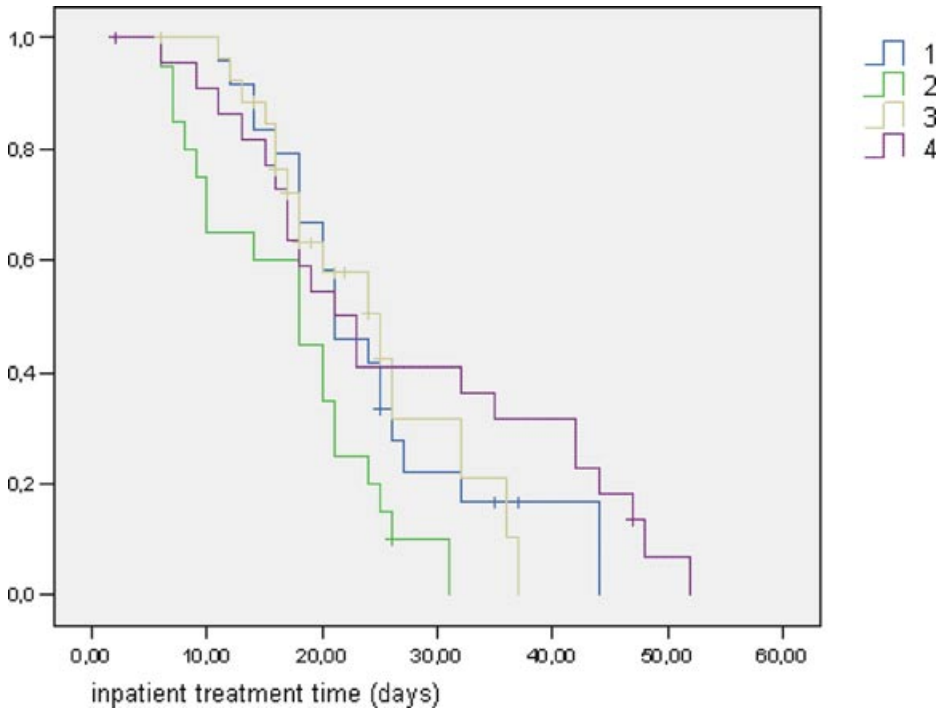


FIGURE 3. Time of Inpatient Treatment: Kaplan–Meier estimation stratified to group of main pathology (1 = prematurity and related complications; 2 = cardiology problems; 3 = congenital gastroenterological diseases; 4 = inborn metabolic diseases).

Table 3 presents the Cox Model for significance and chance (i.e., relative risk) for successful tube weaning. Our sample shows that the chance for successful weaning increases if the tube is removed earlier in the treatment program. 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 the 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, subtype of feeding disorder (Chatoor et al., 1997; Chatoor, Ganiban, Harrison, & Hirsch, 2001; Chatoor, 2002), subtype of interaction classification between parents and child, degree of functional–emotional developmental delay, and the occurrence of birth by Cesarean section. Developmentally delayed children could be weaned as well as others. Surprisingly, our data indicate that the quality of interaction between children and parents does not significantly influence the weaning outcome.

DISCUSSION

Results

The results of this study indicate that the 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 also can be used in severely ill children.

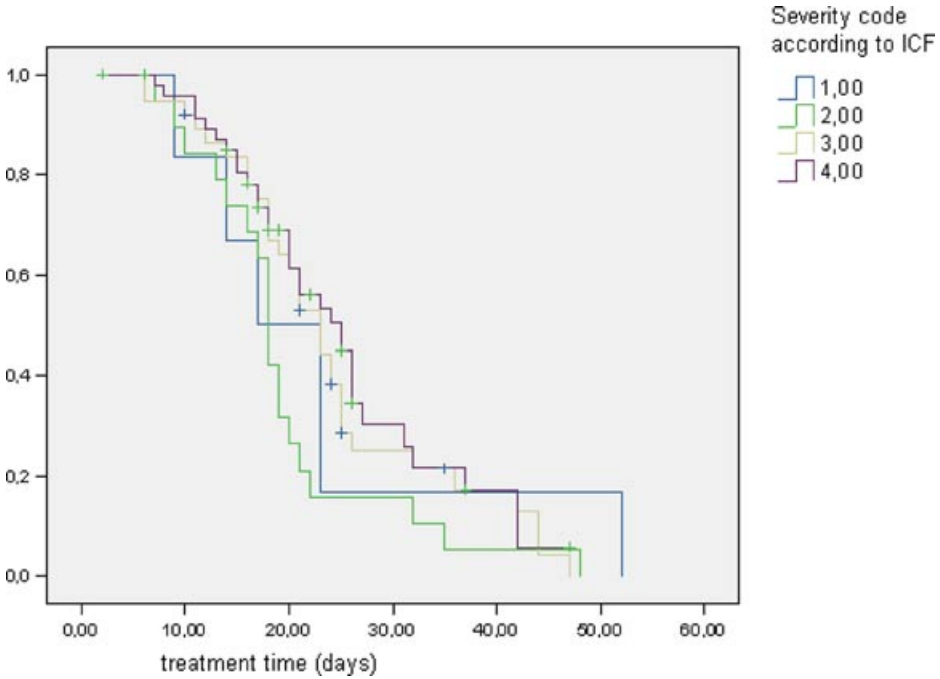


FIGURE 4. Time of inpatient treatment: Kaplan–Meier estimation stratified to severity code according to the International Classification of Functioning, Disability and Health (1 = less severe disabled children, 4 = most severe disabled children).

TABLE 3. Cox Model for Influencing Factors Showing Significance and Exp(B) as Value for the Relative Risk for Weaning (Only Significant Factors Listed)

	Significance	Exp(B)	95.0% confidence interval for Exp(B)	
			Upper	Lower
Time until final tube feeding (days)	.000	.817	.756	.883
Body weight at admission	.003	19.093	2.762	131.998
Body mass index at admission	.034	.262	.076	.906
%Loss of body weight during therapy	.001	.774	.670	.895
DC: 0–3 code for psychosocial stress (Axis 4)	.003	1.723	1.203	2.466
Severity of disease according to ICF	.004	.516	.329	.809
Gestational age (weeks)	.000	.895	.842	.952
Age at admission	.018	.998	.996	1.000
Type of relationship disorder (Axis 2 DC:0–3)	.019	.379	.169	.851
Functional developmental level (Axis 5 DC:0–3)	.024	2.939	1.155	7.476

ICF = International Classification of Functioning, Disability and Health.

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 multimorbid children could be discharged only after regaining full stabilization.

Children with congenital heart diseases were weaned the fastest (Trabi et al., 2006b). This may be due to continuation of oral nutrition in the period before surgery. Thus, most of these children never stopped eating, even though they were supported to gain weight by tube feeding. Because of the continuation of oral intake, we believe that the eating disorder is less severe in these children.

Our study showed that a higher BMI at admission increases the time needed for weaning. Most of these 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 a longer time for weaning because they have more fat mass (which was not measured within this study), and so therefore have less hunger than do those with very low BMI, based on the regulation of hunger by adipocytokines.

Every child included in this study had prior failed attempts of weaning. Most had been hospitalized for long periods, and many of them showed the full range of posttraumatic feeding disorders (Benoit & Coolbear, 1998) with panic attacks (46%), total food refusal (69%), or high levels of anxiety (42%). Nearly all infants treated met the specific criteria of posttraumatic feeding disorder. Additionally, some children showed comorbidity with the subtype of neurosensory impairment; other children showed comorbid symptoms of attachment or individuation disorder.

All patients who were weaned have remained orally fed at follow-up. Two children suffered from primary dwarfism; their growth remained subnormal, but within the range of expectation for their specific diagnosis. All parents reported an overall improvement in various developmental levels such as speech development and 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 that 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 (Blackman & Nelson, 1985; Handen et al., 1986). One model, derived from the Graz Model, allows less severely disabled children to be weaned in a home-based setting (Wilken & Jotzo, 2004). Prematurely born neonates have been weaned using oropharyngeal stimulation techniques (Babbitt et al., 1994; Senz et al., 1996). 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 does 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 *posttraumatic*, as defined by Chatoor et al. (2001), focuses on experiences of direct oral traumatization—mostly single or repeated events of choking or gagging. Another interpretation of the term *posttraumatic* is to focus on the existence of a retrograde mental trauma caused by chronic deprivation from the loving caretaker or repeated and dramatic scenes of separation during long hospital admissions. In the classification as used in our program, we define posttraumatic feeding disorder as shown by the existence of explicit food refusal, food avoidance, turning the head when food is presented, mostly combined by tactile hypersensitivity, disgust, and the reluctance to even touch food. Nearly 90% of the population of tube-dependent children spent their first weeks of life in intensive care units, thus repeatedly being exposed to suction, oral mechanical traumatization, 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 (Strauss et al., 1997), weaning should be the main goal in treatment.

The present treatment costs \$864 (U.S.) per day when applied as inpatient therapy, and the total inpatient treatment cost is approximately \$18,000 (U.S.). The economic and psychological costs caused by gastrostomy tube feeding are estimated to be \$37,232 (U.S.) per year (Heyman et al., 2004). Hospital costs for treatment of associated complications increase the annual cost of gastrostomy tube feeding. The 3-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 and Coolbear (1998) noted, different therapy protocols can be used. The introduction of oral feeding improves the quality of life (Smith, Camfield, & Camfield, 1999; Sullivan et al., 2002), leads to very positive general developmental changes, and reduces the rate of complications (Aquino et al., 1995).

The field of tube feeding has not been 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 (Sleigh, Sullivan, & Thomas, 2005).

In conclusion, as other authors also have suggested (e.g., Axelrod, Kazmerski, & Iyer, 2006), weaning should be the primary goal in treating those tube-fed children 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, and 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 months of 2007)—we have changed the presented inpatient model to a mainly outpatient one and have introduced a computerized data-collection method, the details of which we hope to present in the near future.

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