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Tube Dependence A Reactive Eating Behavior Disorder

Marguerite Dunitz-Scheer, MD, Sabine Marinschek, PhD, Hannes Beckenbach, PhD, Elisabeth Kratky, MD, Almuthe Hauer, PhD, and Peter Scheer, MD

Abstract: *This article focuses on the issue of tube dependence (TD) in infancy and early childhood. The condition occurs in patients after temporary tube feeding and must be considered as an unintended side effect of modern treatment practices affecting young patients reactively. Whereas some recent literature has described small samples of enterally fed children being exposed to certain weaning programs, the particular phenomenon of unintentional dependence has not been discussed. A tube-dependent child remains tube fed although his/her medical condition and developmental potential would allow the transition to oral nutrition. Children with TD show characteristic symptoms such as food refusal and opposition to any oral feeding attempts. They often suffer from additional episodes of vomiting, nausea, gagging, and retching and in some cases develop severe failure to thrive. Parents of affected children get involved as codependents engaged in constant preparations of the next tube feeds. In this situation, families can become obsessed about wanting their child to learn to eat by himself/herself, ending up in intrusive feeding patterns. Professionals tend to make parents responsible for the behavioral aspects of the condition, but the diagnostic shift of TD into a behavioral category will not help solve*

the problem. The development of TD can be prevented if typical symptoms are recognized early and effective tube weaning is implemented. Because therapeutic programs exist, the fate of remaining tube dependence should be prevented. This article presents a first overview of a large sample of tube-dependent infants who had been referred specifically for the exclusive sake of tube weaning.

Keywords: school nurse knowledge/perceptions/self-efficacy; school nurse ratios; school nurse characteristics; qualitative research

TD has been the focus of clinical work and research of our group for the past 15 years. Numerous articles have highlighted this highly specific clientele and have been published in German and English.²⁻⁹

The cited definition covers only the final state of the disorder, when all feeding attempts are vigorously resisted and the child has been tube fed for most of its life. In most cases, the infants are fragile but medically stable survivors of neonatal intensive care or child surgery and show multiple comorbidities covering the whole range of paediatrics.¹⁰⁻¹⁶

“At the same time, a child with a history of any severe medical problem might show stress and discomfort in the feeding situation and will have a higher risk of developing an eating behavior disorder.”

Introduction

The definition of tube dependence (TD) was first published in 2009 by our group in an article on issues of prevention and treatment of this condition. It was defined as “an unintended result of long-term tube feeding in infants and young children.”¹

The rate of formerly premature infants is exceptionally high. A tube-fed infant becomes completely dependent on externally regulated feeding in the absence of any underlying specific medical reason. Tube feeds are given by gravity or by a feeding pump, are continuous or bolus, and made with concentrated formula or standard formula.

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In cases when additional major symptoms like recurrent vomiting, gagging, discomfort, oversensitivity, fussiness, and oppositional and aversive behaviors are present,¹⁷⁻²² the parents are often stressed more than the child. Other commonly reported complications of long-term tube feeding are perforations, infections, dislocations, leakage, and blockage. Different phases and stages of severity of TD must be distinguished. Intervention will only be successful when addressing the specific symptoms of each child individually. Tube feeding also affects the parent's natural instinct for feeding their child normally at a very basic level, often leaving the parent traumatized, desperate, anxious, and seeking help (Atzaba-Poria N, Meiri G, Millikovsky M, Barkai A, Dunaevsky-Idan M, Yerushalmi B, unpublished data, 2010).^{23,24} The impact of the disorder on the parents and caregivers has hardly been recognized.²⁵⁻²⁸ Feeding is an interactive exchange of food and cues, and any emotional imbalance on the side of the caregiver will have an impact on the child. At the same time, a child with a history of any severe medical problem might show stress and discomfort in the feeding situation and will have a higher risk of developing an eating behavior disorder. Unfortunately, a lot of psychological stress factors are responsible for the dysfunctional feeding situations. Exclusive tube feeding always has a nutritional and growth-related aspect (how much of which formula at which times is the child receiving), behavioral aspect (does the child relate to food and meals at all besides being tube dependent), and mind-related aspect (how does tube feeding influence the child and the parent's thinking, feeling, and behavior), which again affects their communication and daily interactions.²⁹

Each of these issue areas mutually influences the other, and the child will not make any developmental changes if no decisions concerning the need for changes (change in tube feeding, changes in thinking, sharing ideas on tube weaning) are made. The lack of specific literature about the existence of this condition is responsible for thousands of tube-dependent children remaining

dependent on their feeding tubes, even though no medical reason demands the continuation of this highly artificial method of nutrition.

Some recent reports in very small samples suggest force feeding or the use of antidepressant and anticonvulsive medication to support the transition from tube to oral feeds.^{16,30} In some cases, the minds of control-seeking adults even favor the option of a child being continuously tube fed as being a most practical way of ensuring complete external control of nutrition. This might sound bizarre but has become an issue in repeated cases of children with failure to thrive when tubes are recommended and placed because of psychological conflicts and severe interactive conflicts around feeding. The academic psychiatric discussion about classification issues of attachment and attachment-related disorders in infancy was enriched in 1996 by Charles Zeanah's³¹ proposition of a new diagnostic category defined as nonattachment relationship disorder. The characteristic features of this group help describe infants and toddlers who did not even have the emotional requirements to develop any form of deviant attachment pattern or any specific psychological reaction to regulating and managing relationships. He suggested that the origin of this emotional and mental disorganization was the complete lack of a very basic sense of awareness of the specific theme of attachment itself because even the most primitive attachment experiences were not present.

Another topic that influenced the writing of this manuscript significantly was the recognition of earlier literature on the existence of a severe medical condition in pediatrics still well remembered in neonatology as retinopathy of prematurity. An awareness of unintended but dangerous side effects of long-term mechanical respiration in newborns with very low birth weight during the 1970s highlighted the need of using less oxygen and weaning premature infants more carefully and gradually off mechanical respirators. The clinical condition of oxygen dependence was the sole urgent matter till a series of publications offered clear proof and showed that a large

percentage of infants born in the late 1960s had better lung function but had become blind as a result of an unintended overdose of oxygen.³²

The diagnostic criteria of existing diagnostic systems do not match the specific features of the growing population of affected patients. ICD10 (International Classification of Diseases) offers no suitable classification for specific feeding or eating behavior problems in infancy and early childhood. In contrast, the DC0-3R proposed a more differentiated classification of the eating behavior disorder group in 2005. The clinical presentation of patients presenting with no other problem than tube dependence demands reliable diagnostic criteria with the goal of facilitating assessment and must allow specific and successful therapeutic interventions to be administered.^{15,33} Precisely this issue is urgent because thousands of survivors of modern neonatal medicine are literally prevented from learning to eat because of the lack of information, lack of diagnostic definition, and the lack of clear guidelines and clinical expertise. We therefore wish to surpass current limitations, highlight this important topic, and offer descriptions of the various developmental levels of different stages and severities of tube dependence in early childhood. By defining specific characteristics of this state we hope to encourage others to comment.

Method

Epidemiological analysis of data was done in a study sample of 114 tube-dependent infants in the period of 24 consecutive months from January 1, 2009, through December 31, 2010. ArchiMed (version 46.2), a program for statistical analyses of medical data, was applied by the Institute for Medical Informatics, Statistics and Documentation, Medical University of Graz. Statistical analysis was performed with PASW 18 (Predictive Analytic Software). All patients included were referred for the specific reason of tube weaning and had undergone repeated prior therapeutic interventions focused on their tube dependence before referral to our center. All children

admitted to the tube weaning program from abroad showed a severity of tube dependence characterized as stage 1 to 2. All the 114 infants had been tube fed for most of their life. They had all undergone recurrent tube weaning trials at home and were considered unweanable. Selection of suitability for our program was performed by preassessment with a specific questionnaire, sent via e-mail; Of the 115 requests for participation in the tube weaning program, 1 was not accepted because of the patient having brain injury and severe dysphagia. The program lasted for 15 working days and was administered on both inpatient and outpatient bases in our clinic. Our method, known as the “Graz Model” has been discussed several times^{2,3,8,24} and relies on 15 years of research by our professionals (pediatricians, psychologists, therapists, and nursing staff).

Results

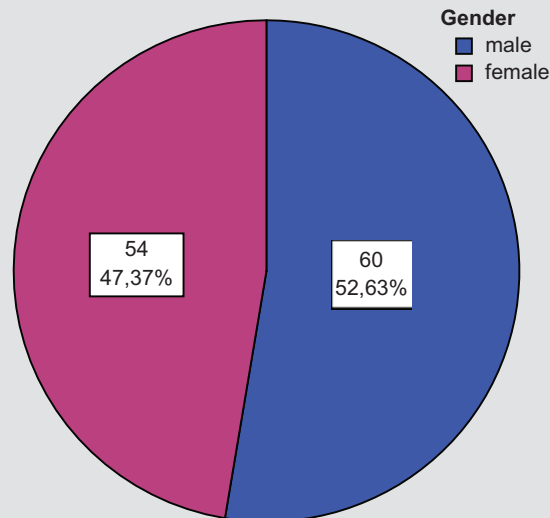
Collecting and analyzing the epidemiological data of this specific and unique sample was the primary goal of the study. On one hand, the investigation of medical diagnosis concerning the underlying preceding medical condition revealed a high diversity and ranged over all diagnostic entities in pediatrics. On the other hand, the presenting features of tube dependence showed an overwhelming stability. As far as gender distribution was concerned, there was a slight preponderance of boys versus girls (52.63% and 47.37%, respectively)—see Table 1. The numbers of percutaneous endoscopic gastrostomy tubes and nasogastric tubes were 58.8% and 41.2%, respectively; see Table 2. The specific kind of tube used to tube feed a specific child did not seem to have much influence on the risk of the development of tube dependence. Further analyses should be done on this issue. The mean age at the time of referral for tube weaning was 2.79 years (standard deviation: 2.56), ranging from 3.5 months to 19.65 years (only 1 of the participants was an adult).

Patients from all over the world joined our program. Most patients came from Great Britain and Ireland (26.32%) followed by Austria and Germany (both

Table 1.

Gender Distribution of Tube-Dependent Infants

Gender	Frequency	Percentage
Male	60	52.63
Female	54	47.37
Total	114	100.00



21.05%). Many patients also came from Australia/New Zealand (11.40%) and South Africa (7.02%); 3.51% were from the United States, and 9.6% came from other countries (Singapore, Sweden, Hungary, Poland, Russia, Italy, Canada, Lichtenstein, Netherlands, India, and Israel); see Table 3. Of the referred patients, 80.7% were successfully weaned within the 3-week program. Another 13.2% left the program partially weaned (they took about 50% to 70% of their food orally), but were weaned completely within 4 to 12 weeks after discharge (100% oral intake). Reinsertion of a tube has not been needed in any case yet; we are able to observe all patients because we offer an 18-month period of aftercare. Among the whole group, only 6.1% could not be weaned at all for several reasons (quitting the program before term, not safe to swallow, and severe brain injuries). Also, we recommended that 3.5% of our

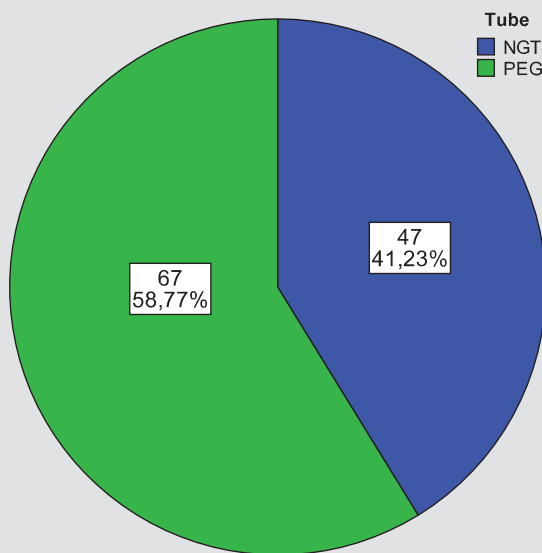
patients change from nasogastric to percutaneous endoscopic gastrostomy tube feeding because of the severity of the underlying medical and neurological condition (see Table 4 for outcomes).

When looking in detail at the phenomenon of tube dependence itself, one finds a variety of presenting symptoms and very different levels of “oral readiness,” which are mirrored in an even greater diversity of clinical progress of each child during the standardized treatment scheme. This was the reason for classifying different degrees of severity and different stages of the condition itself, because weaning any specific, individual tube-dependent child can be an easy procedure needing only 3 to 4 encounters and no specific therapy at all or, on the other hand, needing an extreme level of professional expertise on various levels of intervention in an inpatient setting. The main reason for

Table 2.
Distribution of Tubes

Gender	Frequency	Percentage
NGT	47	41.23
PEG	67	58.77
Total	114	100.00

Abbreviations: NGT, nasogastric tube; PEG, percutaneous endoscopic gastrostomy.



presenting this classification is to describe the complexity and heterogeneity within the seemingly homogeneous group.

Stages of Tube Dependence

In each of the typical stages of tube dependence, a distinction must be made between nutritional, sensory, behavioral, mental, and emotional aspects in the child and the practical and implicit consequences of codependence in the caregivers. These issues have also been addressed in the former work of our research group.⁸

Stage 1. In this stage, 100% of feeding is administered by tube. The child shows indifference or active visual and tactile avoidance or total refusal and oppositional behavior toward anything edible and any attempt at being fed by mouth.

Possibly some water is accepted orally, but this is rare and is not enough to prevent the child from getting dehydrated. This stage of complete dependence on enteral feeding can be found in bright and well-developed children as well as in children with a certain degree of general developmental delay. It can also be seen in severely handicapped children. Any child suffering from dysphagia, the inability to transport any food by oral passage without the risk of aspirating into the lung, might also show strong negative behaviors when in contact with food. This stage of tube dependence is typically associated with visual avoidance, aversive behavior, nausea, or disinterest at the mere sight of food and total food refusal in any situation when food is offered. Even anticipation of a feeding scene by

watching any preparations can provoke negative and anxious reactions. Additionally, the children often show disgust while touching food or any messy texture that reminds the child of real food. Tube dependence also means that the child does not perceive its mouth as its primary location of feeding and will eagerly point out to the tube when hungry instead of wishing to touch, hold, or taste any food by mouth. His or her own sense of identity incorporates the tube as being the feeding organ. This can be observed from about 12 to 18 months of age onward. Tube-dependent children cannot eat, have never learnt to eat, and do not want to eat by mouth as long as full tube feeding is continued. The main characteristic is being used to tube feeding in a neutral or even positive way and showing clear negative reactions to any change in the daily tube feeding routine.

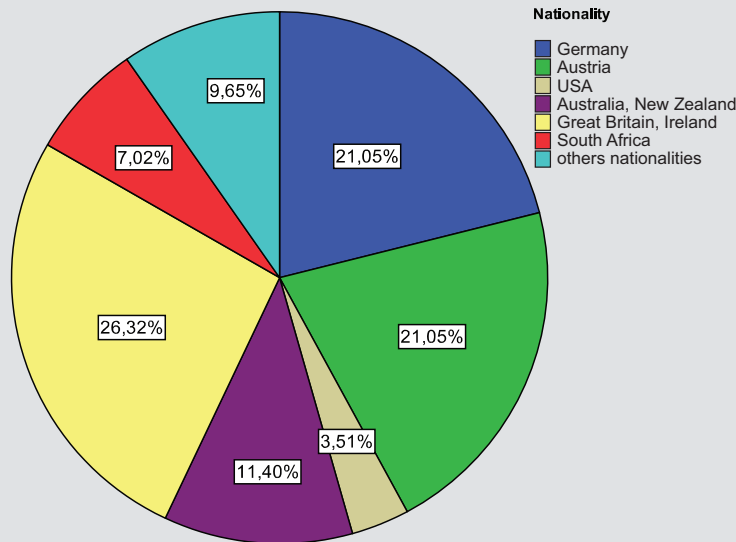
Stage 2. The child is practically fully dependent but will show some oral interest. The child may enjoy touching food, will grasp and hold food, seems curious, and will play with food. The child might even bite and taste mostly solid food, but oral intake constitutes <20% of the total required calories and liquids. The child’s caregiving system is conscious that learning to eat is a realistic goal; oral feeding will be offered on several occasions in a day, but the parents or the medical system involved expect the child to increase oral intake and show better oral skills before tube feeding is markedly reduced. The infant caregiving system lacks the know-how and support but would clearly like to proceed in the direction of tube weaning.

Stage 3. The child is still mainly tube dependent but has 1 to 2 oral meals by bottle, spoon, or cup; the ratio between tube feeds and oral feeds is about 60:40. The medical team in charge has given allowance to increase oral feeds with the aim of weaning, but the child seems somewhat stuck and unable to increase its amount of oral feeding to satisfy the expectations, including growth goals, of the child’s

Table 3.

Countries of Referral

Countries	Frequency	Percentage
Germany	24	21.05
Austria	24	21.05
United States	4	3.51
Australia and New Zealand	13	11.40
Great Britain, Ireland	30	26.32
South Africa	8	7.02
Others	11	9.60
Total	114	100.00



caregivers and medical providers. The meal times are characterized by a friendly but urging atmosphere of constant offering on the parents' side and some pressure and increasing refusal on the child's side.

Stage 4. The child is eating 50% or more normally and is only being supported additionally for up to 50% by the tube. Tube feeding is sometimes only given during the night, which can help the child perceive itself as an eating child during the day and allows participation in day care settings.

Stage 5. The child is mainly (70%-90%) on oral feeds but receives a supplemental feeding of 10% to 30% of its nutritional requirement mostly during the night while sleeping.

In all stages mentioned, a dissociation between the child's general development (motor, speech, and social) and its eating development can be found. A 2- or 3-year old toddler might be perfectly chatting along, walking, playing on a differentiated symbolic level, and able to ride a bicycle but at the same time is not able or willing to learn the first stages of oral self-feeding.

Learning to drink can be perceived as being more difficult than eating solids by the child; infants older than 10 months with good motor skills might often be willing and able to grasp, bite, chew, and swallow solids very well while at the same time refusing to be spoon fed with pureed food and not accepting fluids. The observable behavioral reactions, which are mainly provoked by the sight of food and especially at the sight of food being offered to the child, can be accompanied by sensory issues like oral and tactile hypersensitivity but not necessarily. Any professional wishing to assess a tube-fed infant or toddler is advised to have food visible during his or her first encounter with the child and its family. The food is only to be offered to the parents and siblings, and the child's reactions will be a valuable hint for commencement of any discussion on the topic related to the referral.

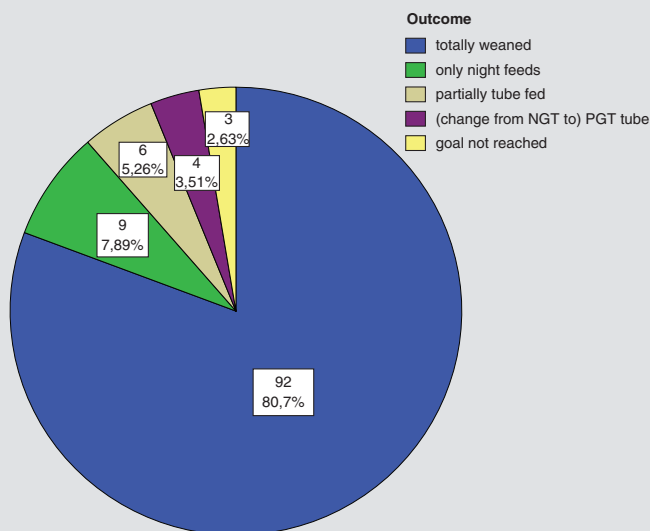
Conclusion

This article wishes to highlight the phenomenon and occurrence of TD. It is not a recommendation or treatment plan for tube weaning. The goal is to enhance early detection of feeding tubes that are not medically necessary anymore and thus take an effective step toward prevention of TD. Another aspect would be to promote more information about negative developmental and functional impacts of long-term tube feeding with the aim of increasing critical assessment of placing temporary tubes in the first place. Medical teams involved in the placement of the tube and nutrition administration should offer a clear aftercare plan also addressing the topic of tube weaning unless the tube is expected to be permanent. The team involved with the aftercare must consist of 1 medical professional able to make decisions about possible changes in nutrition and at least 1 therapist (speech-language therapy, occupational therapy, nutritional counseling, physiotherapy, play therapy, etc). In all cases, starting with premature infants, oral taste stimulation is recommended if swallowing is safe. Tube-fed infants should engage in the family's meal time rituals at any age

Table 4.
Outcome/Success Rate of the 3-Week Outpatient Program

Outcome Within 3-Week Program	Frequency	Percentage
Totally weaned	92	80.7
Left on night feeds at discharge	9	7.9
Left on partial tube feeds <40%	6	5.3
NGT changed to PEG	4	3.5
Goal not reached	3	2.6
Total	114	100.0

Abbreviations: NGT, nasogastric tube; PEG, percutaneous endoscopic gastrostomy.



and as much as possible. It is the “silent” observation of the eating behavior of family members by the child that will “teach” later eating skills. Any showing off or demonstration eating wanting to make the child imitate an adult is counterproductive and potentially harmful. Motivation and self-regulation should be the main reasons behind wanting to eat, so any activity involving food like helping make cookies, touching any kind of food, or participating in shopping for food will be helpful. Oral intake cannot be expected to increase markedly before the tube feeds are reduced to less than 40% of the former intake because of the fact that the child will not be able to feel real

hunger before this decrease in volume. Volume reduction should be done within no more than 3 days under medical supervision to prevent a child getting used to a clearly reduced intake. Tube weaning is a delicate process involving medical, behavioral, functional, and nutritional issues and treatment by a multidisciplinary team. Special expertise is necessary to assist the parents to change the environment of a formerly tube-fed child and prepare him or her for oral eating and drinking.

The authors wish to highlight the need for further research on the population of tube-dependent children and infants at risk. www.notube.at ■

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