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Moving from Tube to Oral Feeding in Medically Fragile Nonverbal Toddlers

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Abstract

The current manuscript describes a 14-week outpatient protocol for transitioning from gastrostomy tube to oral feeding in medically complicated toddlers. The team ensured eating skills were mastered before treating patients for 8 weeks with continuous gastro-jejunal drip tube feedings and low-dose tricyclic antidepressant and/or gabapentin. We prescribed six weeks of megestrol for hunger provocation while withdrawing tube feedings. A chart review after treatment demonstrated 9 subjects were exclusively eating orally and one was eating 50% orally.

Keywords

Tube feeding; Oral feeding; Feeding behavior; Pediatric feeding; Outpatient program; Pain rehabilitation

Introduction

Infants with long neonatal intensive care hospitalizations may lose opportunities for learning to eat and may associate eating with pain or discomfort (1). Although the causes for prolonged hospitalizations often resolve with treatment, a tube feeding requirement may persist for months to even years. As the use of gastrostomy tube feeding has risen, so have the challenges associated with weaning a child from tube to oral feeding.

There are several methods for achieving transition from tube to oral feeding, but no optimal solution. Many programs consist of intensive outpatient or even 2-3 week long inpatient stays (2-5). Such intensive programs can cause family disruption, distress, and financial burden. Other studies include several case reports of behavioral interventions with only moderate success (6-8).

Few studies have been published examining the effectiveness of outpatient feeding programs (9) likely because of the relative dearth of such programs. One theory has suggested some toddlers refuse to eat because they have chronic upper chest or abdominal discomfort which

is worsened by eating. This results from pain nerve sensitization with hyperalgesia and allodynia (1). Because many medically fragile toddlers have experienced gastrointestinal pain, approaching the tube to oral feeding transition from a pain management perspective may be advantageous. The current study utilized such an approach (1,10) to transition nonverbal children from tube to oral feeding. The objective of the current study is to report a multidisciplinary outpatient method for moving nonverbal children from tube feeding to exclusively oral feeding.

Patients and Methods

We conducted a chart review for all nonverbal toddlers who underwent an attempt to move from tube to oral feedings by the University of Kansas Medical Center Multidisciplinary Feeding team from 2004-2007, resulting in 9 subjects. Their mean age was 27.3 months (SD = 15.6), and ages ranged from 7 months to 52 months at the initial visit. Upon starting this protocol, all nine subjects received 100% of their calorie intake through a gastrostomy tube. The medical or developmental diagnoses of the toddlers are shown in Table 1.

Prior to initiating the protocol, 5 of 9 participants had undergone esophageal and antroduodenal manometry with normal results. Four sets of parents refused manometry, preferring a “trial and error approach”.

As recommended by many experts in the field (11), our feeding team was comprised of a multidisciplinary group, including pediatric gastroenterologist, pediatric psychologist, occupational therapist, and dietitian. The feeding team met as a group with each patient and caregiver(s) to complete a thorough assessment of the child's oral motor skills, behavioral strengths and weaknesses, nutritional status and growth pattern, and gastrointestinal symptoms, as well as to observe a typical meal. At the end of the initial session, recommendations were made to caregivers related to oral motor skills, behavior modification, nutrition, and medication for implementation at home.

Transition Protocol

Prior to beginning the medication, the team performed a thorough assessment to ensure that each child possessed the oral motor skills necessary for eating (i.e. chewing, lateralized tongue movement; see Table 2). Skills necessary for eating included oral skill development at or near the child's developmental age. These skills supported the ability of the mouth to coordinate and control food that is nutritionally appropriate and adequate for growth (12). If oral skills were below what would be expected, then the child may not have had the strength to support adequate eating. If the move to all oral feedings was accomplished prior to age 2 years and there were no other concerns related to motor or sensory development, then there is a reasonable expectation in the child's ability to develop more mature eating patterns. Head, neck, and trunk support were assessed as they are necessary not only to support the child's ability to control food in the mouth, but also for control when swallowing and for respiratory stability (13). Finally, all sensory processing issues were evaluated and managed or treated prior to beginning the protocol, because untreated sensory processing issues may impair the ability to eat.

The team also provided guidance related to eating behaviors to the child and family and made certain that the toddler and family had the necessary mealtime behaviors (See Table 3). Behavioral skills were assessed through interview and observation of a meal in the clinic. Behaviors necessary for mealtime included coming to the table willingly several times per day, remaining seated throughout the meal, consuming some food by mouth willingly, and parental control over timing of meal's end. If behavioral skills were not sufficient, families were trained to meet minimal criteria prior to initiating the medication.

After the oral motor and behavioral conditions were met, the protocol moved on to with amitriptyline (1mg/kg/day) or gabapentin (10mg/kg TID), as well as continuous drip gastrojejunum tube feedings (20 hours/day). We began with post-pyloric, continuous drip feedings and one drug. If the patient had a history of poor sleep or diarrhea, we started with amitriptyline 0.25-0.3 mg/kg/dose at bedtime because amitriptyline not only relieves chronic pain, but also reduces stool water through its anticholinergic effects, and improves sleep through antihistaminic effects (14-16). We increased the amitriptyline dose by 0.25-0.3 mg/kg/day each week to attain a maximal dose of 1 mg/kg/day. If the child had a history of seizures or heart disease with conduction abnormalities we avoided amitriptyline, but began with gabapentin 10 mg/kg twice daily, because gabapentin not only reduces chronic pain, but also raises the seizure threshold and does not provoke cardiac arrhythmias as overdoses with amitriptyline (17). After a week we increased the dose to 10 mg/kg three times daily. Patients returned for their second visit 8 weeks later. During this visit, the team answered questions, provided support, offered guidance to the child's parents/caregivers, and we prescribed appetite stimulant megestrol (3mg/kg BID). We continued the pain medications amitriptyline or gabapentin. Five days after beginning the appetite stimulant, tube feedings were progressively reduced. This process lasted between 10 days and two weeks until tube feeding was discontinued. The appetite stimulant was discontinued after 6 weeks to avoid potentially serious side effects of longer treatment with this medication. Weight was monitored weekly at home and reported to the team. Families were encouraged to contact team members with questions or concerns. The other medications were stopped after 6 months, by weekly titration to smaller doses.

Results

All subjects were able to complete the transition protocol without negative side effects. At the end of this 14-week protocol, all 9 patients received 100% of their caloric intake orally. Eight of the nine were able to maintain their weight over time and never required additional tube feeding. One patient with cerebral palsy had difficulty maintaining his weight due to oral motor stamina issues. At the time of writing, his intake is 50% oral and 50% gastrostomy tube. Therefore, all subjects had improvement in oral feeding during the 14 week outpatient program. Eighty-nine percent of subjects maintained *exclusively* oral feedings following the 14 week protocol.

Discussion

This study described an outpatient transition program based on a pain rehabilitation approach. There are several methods used for moving children from tube to oral feeding that focus on behavioral, oral motor, and medical issues (18). However, many involve extended inpatient stays or intensive day treatment. Other published outpatient studies have reported limited success, even when taking a multidisciplinary approach including medication and cognitive behavioral family therapy (1). Several case reports using behavioral interventions achieved only moderate success (6,7).

A recent case study used a method similar to the current study, but instead of using medication to treat *physical* pain, they conceptualized the oral feeding difficulties as emotional and psychological in nature. The case study reported the successful use of fluoxetine to treat two-year-old twins who became very distressed and agitated during oral feeding following several invasive gastrointestinal procedures (19). Researchers noted that their fear and anxiety decreased with treatment, which allowed the twins to discontinue tube feeding within several months.

To our knowledge, the current study is the first published protocol to describe an outpatient program for transitioning medically fragile toddlers from gastrostomy tube to oral feeding that

uses a pain rehabilitation model. While we did not specifically assess physical pain during the transition, we hypothesize that, at least for some children, a pain management approach may be effective for moving children from tube to oral feedings. In addition, these changes were accomplished in an outpatient setting, preventing children and their families from having to endure stressful, expensive, and unnecessary inpatient stays.

In the case of our subjects, we hypothesized that gastric distension from a routine meal caused discomfort, potentially stimulated retching against a fundoplication in an attempt to avoid the discomfort, and therefore maintained or further sensitized pain nerves. Continuous drip post-pyloric feedings treated pain by imposing an 8 week period of no gastric distension and so no retching, thus allowing pain nerves to return to normal sensitivities. This hypothetical return to normal nerve sensitivity was presumably accelerated with drugs used to treat chronic neuropathic pain in children and adults. Amitriptyline and other tricyclic antidepressants have been used for the past 20 years to treat irritable bowel syndrome (14,15). The amitriptyline doses used for pain treatment are a magnitude less than the doses used for treating depression, and pose no cardiac risk in individuals without pre-existing cardiac conduction defects. The anti-seizure medication gabapentin has been used for chronic neuropathic pain (20), and quiets irritability in neurologically impaired children (21).

Megestrol has the potential to increase negative behaviors including insomnia, hyperactivity, and irritability (22). However, patients in the current study experienced no problems related to megestrol.

There are several limitations to the current study. First, the small sample makes it difficult to generalize about the effectiveness of this approach. Second, this is a retrospective chart review rather than a randomized controlled trial, limiting the scientific rigor of the findings. Finally, the program was not fully successful in one case of a child with oral motor difficulties limiting his stamina and preventing him from maintaining his weight with exclusively oral feeding.

This study is the first to examine the effectiveness of a 14-week outpatient feeding protocol based on a pain rehabilitation model for the transition from tube to oral feeding in toddlers. The protocol was successful in 89% of the sample in maintaining exclusively oral intake. A randomized controlled trial comparing this pain rehabilitation protocol to standard care group with a larger sample should be conducted to better assess the value of the protocol.

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Table 1

Participant Information (N = 9).

Age in Months at Initial Visit	Gender	Diagnoses
13	Male	32 week gestation; developmental delays
38	Female	Triplet; 26 week gestation, GERD [*] ; failure to thrive, diffuse esophageal spasm, cyclic vomiting syndrome
8	Male	Failure to thrive; GERD, hiatal hernia; Ring 21 chromosomal abnormality
52	Male	Cerebral palsy
7	Female	Ventricular septal defect
37	Female	Failure to thrive
26	Female	Twin; 30 week gestation; GERD
26	Female	Twin; 30 week gestation; GERD
39	Female	Down's Syndrome

^{*} GERD = Gastro esophageal reflux disease

Table 2
Oral-Motor Skills Required Prior to Starting Protocol

SKILL	Assessment Method	Description	Supports Oral Skill
Age- appropriate strength and coordination of the oral cavity	Observation Manipulation	Adequate range of motion, strength and coordinated movement of the lips, tongue, jaw	The manipulation of food, either liquid or solid that is appropriate for the child's developmental age or would support adequate nutrition.
Head/Neck/Trunk Support	Observation Manual Testing if necessary	Strength and control of the head, neck, and trunk to provide midline stability of the body	Control of the head, neck and trunk support erect posture and alignment so that the mouth is able to manage and manipulate food and there is support surrounding the swallow.
Sensory Processing	Observation, Short Sensory Profile (23) Interview with family and other care givers	No overt sensory processing issues that interfere with daily life activities, specifically eating/feeding	The ability to organize sensory input supports the mouth's ability to control and manipulate food without reaction to texture, temperature, etc. This in turn supports a safe swallow. Difficulties with sensory processing may set up food aversions that may or may not be directly related to oral skills.

Table 3
Behavioral Skills Required Prior to Starting Protocol.

Name of Skill	Descriptor
Regular Meals	Coming to the meal at least 2-3 times per day, willingly.
Limited Grazing	Child does not simply graze throughout the day, but participates in structured family mealtimes.
Same Location	Daily meals take place in the same location.
Meal Length	Meal length falls between 10-20 minutes.
Meal Distractions	There are few distractions during mealtime (ex. TV), that occur on a routine basis. A child who requires distraction in order to take bites is not eligible.
Family Mealtime	The child and family eat meals together on a regular basis.
Structured Start & End	The parent dictates the start and end of the meal with a simple command such as "It's time to eat" or "You may get down now."
Parent Behavior During Meals	Parent behavior during meals is appropriate with limited coaxing, never any forcing of food, and no yelling or threatening.
Force Feeding	There is never any forcing of food or other objects into the child's mouth.
Meal Demeanor	The child is neutral toward or enjoys the mealtime as evidenced by voluntarily placing food in their mouth (or allowing an adult to do so) without crying, turning their head away from the spoon, batting at the spoon, etc.
Good Presentation of Food	An appropriate amount and variety of foods are presented in a calm and relaxed manner, and parents do not sneak the spoon into the child's mouth but rather announce each bite (if feeding the child).