



Pediatric Feeding and Dysphagia

Dear Fellow Feeders:

Hello! Well, this is the last newsletter of this year. Time has flown by again! I hope that this forum has provided helpful information and expanded your thinking in this exciting and challenging field. I have thoroughly enjoyed putting it together.

In this issue we are fortunate to have three guest authors. Debra Beckman, MS SLP CCC-SLP writes on oral stimulation, Cathy Fox, MS OTR discusses the importance of biomechanical alignment, and Nancy Gray MS, RD, LDN summarizes an article on maternal feeding stress.

For those of you on the

east coast, I would like to highlight a conference I am helping to put together. It will be a multi-disciplinary workshop for pediatric feeding and swallowing therapists and interventionists on May 18-20 in Raleigh, North Carolina. Speakers will include Dr. Peggy Eicher, developmental pediatrician, Cis Manno, SLP, Cathy Fox, OTR and Mary Lou Kerwin, Ph.D, psychology. These are my old mentors from the feeding team that used to be at Children's Hospital of Philadelphia. If interested in more information, go to www.wakeahec.org or call Toni Chatman, Wake Ahec at 919-350-8547.

You'll find a postcard on the back page to mail in if you would like to re-subscribe to next year's newsletter. I hope to cover topics such as highlighting in-patient feeding teams, sensory vs. motor therapy, sensory integration, cranial nerve function, therapy techniques and evaluation. And we'll continue the articles on case studies and new research. Volume II will begin in July.

Thank you for the feedback this year! Good luck and have a wonderful summer.

Krisi Brackett

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Special points of interest:

- ☺ Guest authors
- ☺ Case studies
- ☺ New Research
- ☺ Continued series on GER

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Anti-reflux Surgery: The Nissen Fundoplication

The nissen fundoplication was developed by Dr. R. Nissen in 1959 for the cessation of gastroesophageal reflux (GER). This surgery involves a 360 degree wrap of the fundus (top section of the stomach) around the

esophagus. Typically, a single anterior row of sutures secures the wrapped stomach to the esophagus. Other types of fundoplication are performed and involve various degrees of wrap. "Facilitation of care,

reduction in pneumonia and vomiting, and improvement in the general health and survival of these children have been major goals of fundoplication and gastrostomy." (Smith et al.,

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Anti-reflux Surgery: The Nissen Fundoplication

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1992) Gastroesophageal fundoplication is currently one of the three most common major operations performed on children in the U.S. (Fonkalsrud EW, 1996) A 90% success rate of eliminating reflux in the perioperative period has been reported in the literature.

According to the Children's Motility Disorder Foundation's information (www.motility.org), the key to a successful fundoplication is careful selection of appropriate patients. Preoperative diagnostic testing is critical in determining whether a patient is an appropriate candidate for a fundoplication. Often the decision to operate follows attempts at behavioral and medical management of the gastroesophageal reflux disease.

Recurrent GER following fundoplication is a challenging problem with reported incidence of 0% to 12%. A study by Negre & colleagues (1983) reported a 20% failure rate over a ten year period. Many believe that the failure of a fundoplication is typically due to an underlying disorder such as poor gastric emptying due to impaired mobility. Failure can also occur secondary to disruption of the wrap, slippage of the stomach within the wrap, hiatal hernia, small bowel obstruction, dumping syndrome, and excessively tight wrap.

Subtle post-operative complications include abdominal distention (gas bloat), a change in eating habits, and solid food dysphagia. Oral dysfunction has also been reported following a nissen fundoplication. Specifically, symptoms include severe gagging and retching, poor oral intake with aversive reactions to the presentation of food such as lip pursing, head shaking, turning away, and crying. (Borowitz, 1992)

Borowitz et al (1992) explain that while they have observed a variety of complications following Nissen fundoplication in typically developing children, they have observed much more dramatic changes in children with neurologic impairment. The etiology for this is unclear. Swallowing neurons receive strong inhibitory input from vagal nerve afferent fibers. Some of these fibers may arise from the numerous mechanoreceptors in the distal esophagus, gastroesophageal junction, and gastric fundus. The fundoplication may be causing chronic mechanoreceptor activation which inhibits spontaneous activity in the central swallowing center in the brain. Typically developing children may be able to overcome these inhibitory inputs, while children with neurologic impairment may not.

Typically, at our facility (UNC), a child who is considered for a fundoplication receives an upper GI and pH probe, and if appropriate a gastric emptying scan or endoscopy. They have usually been on medical management for several months prior to consideration for surgery. The other scenario concerns children receiving gastric tubes. Because having a g-tube may increase the risk of GER, they are routinely evaluated so that the surgeries can be performed simultaneously if needed.

Some clinicians feel this surgery is used too commonly causing set backs in oral acceptance of foods while others feel it is necessary to protect against uncontrollable GER. While therapists and feeding specialists may not have a say in whether a child receives a nissen fundoplication or not, it is important to recognize changes in eating habits that may follow the procedure. If the child is having feeding difficulties, a history of feeding acceptance and behavior pre and post surgery should be taken.

Usually children receiving fundoplication are taken off of their reflux medication after surgery. If delayed gastric emptying was problematic before surgery, a child may need to remain on medical management. Tube feedings may need to be slowed to accommodate a smaller stomach or to decrease retching behaviors.

An alternative to this surgery is the use of a jejunostomy tube to bypass the stomach temporarily. This allows the stomach to rest from chronic refluxing while nutrition is given via the intestine.

It is important for professionals involved with feeding to understand the pro's and cons of this commonly performed surgery. This will allow us to better serve children who continue to have feeding problems following a nissen fundoplication.

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FYI...

PELVIC STRAPS CAN BE USED SUCCESSFULLY TO ASSIST WITH SUPPORTED SEATING DEVICES. THEY CAN BE ATTACHED TO THE BACK OF THE CHAIR WITH BOLTS AND ARE SECURED TIGHTLY AROUND THE UPPER THIGH LOCKING THE PELVIS IN PLACE. IN SOME CHILDREN, THEY CAN PROVIDE BETTER SUPPORT THAN A LAP BELT OR BAR WHERE THE CHILD CAN SLIDE UNDER THE STRAP GOING INTO A POSTERIOR PELVIC TILT THROWING ALIGNMENT OFF. CHECK OUT ADAPTIVE EQUIPMENT SYSTEMS.

The Importance of Biomechanical Alignment in Feeding

By Cathy Fox, MS OTR, Private Practice, Frederick, MD (301-788-5500)

Pediatric feeding and swallowing problems come in all shapes and sizes. The severity of the problem is directly related to fragility of the child and the degree of discomfort, dysfunction, and time needed to eliminate or fully manage the problem. Because of these factors alternate means of feeding (i.e. adaptations made by the child or implemented by the treatment team) can result in limited and/or missed opportunities to practice the patterns and skills that are required for successful oral feeding. This is the ability to meet ones nutritional needs while simultaneously building and refining skills that will enable oral feeding to evolve to higher, more complex textures.

Depending on your discipline and training, your approach to feeding and swallowing may be predominated by sensory-motor (i.e. oral stimulation) or behavioral management. Although these approaches are immensely different, they are not mutually exclusive and must occur cooperatively so that appropriate skill learning can occur.

Generally, what is biomechanical alignment? It is not just sitting up straight. It involves the relationship of bones, soft tissue, and muscles to obtain the best function possible. The importance of biomechanical alignment for effective swallowing is understood. What is not understood is that biomechanical alignment is

important for the development of sensory and motor awareness in the mouth, pharynx, larynx, esophagus, stomach, intestines, lungs, and rib cage.

We are born as reflexive beings functioning within a very compact structure. Our sensory learning begins from the inside e.g., how our tongue moves within the confines of the oral cavity and transports liquid into the pharynx. The awareness of our body is shaped by the physiologic cues and reflexes, which in turn shape our interaction and learning of our bodies and the world around us.

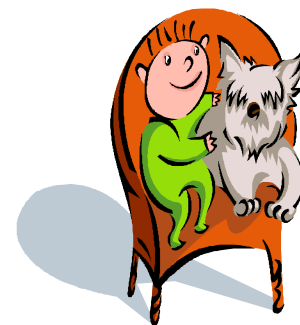
For example, a child with multiple medical issues may not be able to be held or experience different positions due to tubes, lines, necessary medical monitoring, and/or abnormal tone and posturing. Because of this, the very basic experiences and learning upon which the child is to build skills is markedly changed. Biomechanical alignment obtained through proper positioning should be considered a critical means of swallowing and feeding therapy. It enables the child to practice breathing, secretion management and swallowing throughout the day in biomechanical alignment that will lead to maturation and skill

development. It is critical to understand that good positioning is as effective dysphagia therapy as anything done within the oral cavity. The difference is that this therapy occurs without a therapist present and should go on consistently during the day so that the time spent in direct therapy can build on this foundation.

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The above article was submitted by Cathy Fox, OTR, CfoxOT@aol.com.



An Oral Motor Perspective on the Search for Oral Stimulation– Thumbs, Pacifiers, Mouthing Objects and Biting by Debra Beckman, MS CCC-SLP, Beckman & Associates (C)June, 1995

From the first month of gestation, humans seek oral stimulation. The infant first finds this oral input from the amniotic fluid as the fetus sucks and swallows in the womb. The fetus also has been seen on ultrasound images placing the thumb into the mouth. The pressure and movement within the oral cavity tell the brain where the mouth begins and ends. Without such input, the location and boundaries of the mouth are uncertain to the infant. All that lip, cheek, jaw and tongue movement keep the eating machine in peak muscular condition. Movement against resistance is the best way to build strength. Repetition of movement is the best way to refine and develop muscle control. At birth, the infant frantically searches for something, preferably the breast, to suck on. It is a reflexive pattern to insure nutritional intake. The mouth is equipped with lots of sensory receptors, ready for and craving stimulation. The mouth is the exploration cave of an infant. Since vision is not yet well developed, the mouth is the place for touch, taste, texture, with the added bonus of smell accompanying the oral experience. Early on, anything that can fit into the mouth is accepted for exploration.

As the infant matures, the child gradually begins to discriminate edible from nonedible items. But keep in mind that even as adults, we all continue to receive pleasure and comfort from a multitude of oral and facial stimuli. As you are reading this, you are probably touching your face, or receiving input another way, such as chewing on a pen or pencil, or finger nail. You might be giving yourself input by changing the position of your jaw, or closing your lips together with intermittent pressure. Chewing gum or drinking a beverage are other popular adult ways to get oral stimulation.

Baby ways to get stimulation are to suck or chew on things that are easy to reach, such as thumbs and toes. Pacifiers provide opportunities for non-nutritive sucking. Often pacifiers provide more comfort to the caregiver - the baby's mouth is full, so the crying is reduced. Body parts (thumbs and toes) are dynamic, moving and changing shape in the baby's mouth, providing a wide variety of pressure and movement. Pacifiers have a static shape. The stimulation is constant at the center and front of the mouth. The movement of the lips and tongue are constant, without the variety so necessary for the continued development of internal jaw stability and muscle strength needed to chew and later to speak.

For an infant with normal muscle tone, development occurs without any major interventions by the caregivers. For the infant with abnormal muscle tone, development of oral motor skills becomes more problematic, often with abnormal patterns of movement used to complete every day activities such as swallowing secretions, drinking, eating, vocalizing, chewing, and speaking in words or phrases. Because the muscles are out of balance and do not give consistent pressures within the mouth, the individual may seek such input from external sources, such as clothing, toys, or other items. Many of these individuals have not progressed from pureed or soft foods, and so are not receiving input to the jaw through chewing. The posterior area of the mouth may be receiving little or no input because of gagging (with or without vomiting).

The sensory input for the mouth is important, and the craving of such input does not decline for individuals on pureed diets. It may be increased, resulting in pica - the eating of non-edible objects. Some individuals attempt to increase sensory input at the mouth by biting themselves, or others within their reach. Telling someone to stop putting everything into his or her mouth, or punishing him or her for doing so, does not address the underlying sensory needs. By completing a specific baseline of the individual's oral motor skills, specific input can be provided in controlled ways to enhance the muscle balance and internal muscle pressures the person should have, thereby reducing the constant craving for additional external input (mouthing of non-edible items).

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Case by Case

L.S. is a 10 month old full term female born with Pierre Robin Sequence (a craniofacial disorder characterized by U-shaped cleft palate, micronathia or small jaw, and retracted tongue). She received a tracheostomy shortly after birth due to airway obstruction and has had ongoing feeding problems since birth. Typically, we have had success feeding these patients in a sidelying position to avoid airway obstruction using the Haberman Feeder or Pigeon bottle.

Feeding problems have persisted over the 10 months and include poor intake (small volumes), long feeding times, refusal to nipple feed by pulling away, arching, or becoming irritable, gagging and retching, and intermittent vomiting and spitting up of clear mucous. Initially, L.S. received bottle feeds with supplemental nasal-gastric tube feedings. Her formula was changed several times including Similac, Enfamil,

Isomil, Alimentum, and Carnation Goodstart without much success. She has also been tried on various combinations of medication for reflux such as zantac, prilosec, cisipride, and reglan.

An initial Modified Barium Swallow Study (MBSS) was performed at 3 months revealing a coordinated oral-pharyngeal swallow without aspiration. Several months later, reflux testing was performed (an upper GI, pH probe, and gastric emptying scan) resulting in a diagnosis of mild GER. At approximately 5 months, she received a gastric tube without nissen fundoplication to supplement oral feedings. Her family has worked diligently to improve oral feedings with limited success.

At 9-10 months, L.S. had frequent admissions to the hospital for trach infections and intermittent vomiting and her family began to notice formula in her trach after bottle feeding. A second MBSS was done. This showed mild discoordination but no frank

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On the Research Front... Oral Feeding in Infants

Lau, C & Hurst N. (1999). Oral Feeding in Infants. *Curr Probl Pediatr*, April, 105-124.

This review examines characteristics of the infant's ability to feed orally to provide an understanding of when the introduction of oral feeding is safe and how successful feeding can be achieved. Section I deals with the mechanics of sucking during bottle feeding with an emphasis on sucking and coordination of the suck-swallow-breathe pattern. Section II discusses breast feeding and how it differs from bottle feeding. Section III focuses on clinical management of infants with sucking dysfunction emphasizing a multi-disciplinary approach.

The authors feel that assessment of infant readiness to feed is not well developed. Premature infants are generally offered oral feedings after 33 - 34 weeks post menstrual age. Gaining a better understanding of infant readiness has become imperative because of the large numbers of infants who survive premature births and cannot feed readily because of immaturity or dysfunction.

A variety of methods used in studies are described and critiqued for studying sucking. The first method studies the number of sucks by measuring the number of pressure changes inside the nipple or the bottle. This method does not allow for the distinction between suction and expression or for accurate measurement of the force exerted by the subject because the pressures monitored are dampened by the rigidity of the nipple that is used. This method has been adapted with a micro-video camera placed inside the nipple to observe jaw and tongue movement.

The second method monitors sucking by means of a catheter inserted near the nipple hole. This allows for accurate measurement of the frequency and amplitude of suction, but it does not measure ex-

pression.

The authors state that the two methods described distinguish between coarse and fine structures of sucking. Coarse structures mean the number and duration of sucking bursts and pauses. Burst is the time spent sucking and pauses possibly indicate fatigue. Fine structures include the number of sucks, the interval of sucks, and amplitude within a burst. The authors feel that this is not representative of the milk transfer that occurs during normal bottle feeding because the nipple chamber is not filled with milk.

Lau and Hurst devised a third method in response to the previous methods. The nipple chamber is filled as it is during normal bottle feeding, and suction and expression components are monitored as well as swallowing and breathing. Because milk transfer is recorded at the same time, assessment of feeding performance as a function of the infant's sucking ability (amplitude, frequency) and/or area under the curve of suction and expression, and ratio of suction and expression per swallow are possible.

In section I, the development of sucking is discussed as well as highlighting past research. A tight coordination between activation of perioral muscles and sucking pressure is shown. Also discussed is evidence showing that at 26-29 weeks gestation, an infant may use a premature sucking pattern consisting of only expression without suction that can be an effective oral pattern.

In section II on breast feeding, maternal factors such as nipple shape, degree of elasticity, and protractility may interfere with per-

formance. Latch on does not imply successful breast feeding because poor breast emptying may occur if compression of the lactiferous sinus does not occur. Milk composition, positioning techniques, and infant sucking are also discussed.

In section III, the clinical management of feeding disorders is highlighted. Feeding team members, the typical sequence of events, and treatment techniques are reported.

The authors hope the reader will have a better understanding of the current research and information on the oral feeding of infants. They stress that as professionals we have much to learn in this area.

Maternal stress in caring for children with feeding disabilities

Adams RA, Gordon C, and Spangler AA: Maternal Stress in caring for children with feeding disabilities. Implications for health care providers. *J Amer. Diet. Assoc.*, 99 (8): 962-966.

This article looks at stress associated with feeding children with disabilities from several angles: (1). The stress of mothers of children with feeding disorders as compared with the stress of mothers of children with other disorders, (2). The stress of mothers of children who are tube fed as compared to that of mothers of children with disabilities

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On the Research Front...

who are orally fed, (3). The types of stressors experienced, and (4). The coping resources of the mothers. Subjects were 32 mothers of children with disabilities who attended a private rehabilitation facility in the Midwest and the tool was a standardized questionnaire with additional open-ended questions. Most of the children were diagnosed with brain injury or cerebral palsy, were males and were less than 12 years old (53% were less than 5 years old).

Interestingly, there was no statistical difference between the reported stress level of mothers of children with feeding disability over that of mothers of children with other disabilities. The authors suggest that the small sample size may have been a limitation here.

In the mothers of children who were tube fed there was a significantly greater stress level in the area of parent and family problems, but not in other areas. Lack of free time was cited as a stressor by 75% of these mothers. Only one of these mothers indicated that her husband was a source of stress relief, only 25% relied on friends for stress relief and none received support from a baby sitter or from participating in sporting activities. For mothers of non-tube fed children, half reported friends provided support and 25% relied on their husbands for support. Formal support groups were only being used by 3 of the mothers, but it is not clear if this is because such groups are not available or if the mothers are unable or not interested in participating in one.

Based on these findings, the authors make several suggestions for health care professionals to help mothers of children who are tube fed: (1). Proactive recruitment of fathers and/or friends to participate in the training

on use of tube feedings and care of the tube fed child, (2). Public education so that mothers of tube fed children can feel more comfortable in public settings. (3). Improved graduate and undergraduate education of health care professionals on the stresses faced by families of tube fed children, (4). Implementation of support groups for mothers of children who are tube fed, even though it's not certain if they'll use these groups if available. They also suggest that videotapes of meal-times should be used to help make suggestions for inclusion of the tube fed child in the family's interactions.

* Review Submitted by Nancy Gray, MS,RD,LDN, Nutritionist, Boone DEC, 828-265-5391, nancy.ay@ncmail.net

Case by Case

(Continued from page 5)

aspiration, although, barium was seen in the trach tube after the study. Because of this, a fiberoptic endoscopic evaluation of swallowing (FEES) was done a few days later which showed moderate dysphagia. L.S. had trace amounts of residue in the pyriform sinuses which was mixing with her saliva and overwhelming her. It was subsequently aspirated over the aryepiglottic folds and through the posterior commissure. Aspiration occurred after the swallow with all liquids but not with puree. We recommended a temporary stop to oral feeds, dysphagia therapy, and reflux management since she continued to vomit several times per week and sometimes daily.

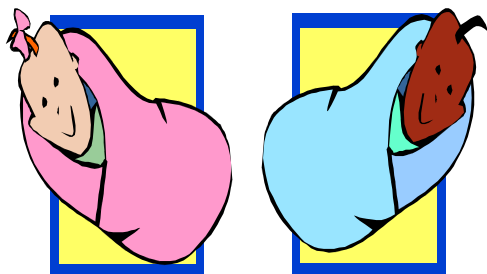
Her GI physician opted for a G-J tube because she had a history of responding poorly to medication. J tube feeding requires continuous feeds. At first, the continuous feeding rate was set too high and L.S. had vomiting of bile. This was adjusted and she quickly had a relief of vomiting which along with her npo status allowed her chronic trach infections to heal.

The SLP worked on secretion management through chest PT, therapy to increase trunk tone, oral stimulation, and began limited trials of thick puree via spoon. L.S. has shown slow improvement and is now transitioning to bolus g-tube feeds and increasing the volume of oral feeds she can handle.

In a few months, (at one year of age), L.S. will undergo surgery for her cleft palate at which time it will be recommended that she come off the bottle. This is due to the danger of the nipple rubbing against the new sutures. Therefore, in the course of our intervention we have chosen not to reintroduce the bottle but to work with cup and spoon feedings.

The use of the j-tube provided L.S. with relief from the chronic GER and GI discomfort she had been experiencing. Her trach infections healed and her saliva management improved which has allowed her to practice safe swallowing effectively.

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