

Pediatric Feeding and Dysphagia Newsletter

Dear Fellow Feeders:

Finally, our July issue!!! I must offer many humble apologies for the tardiness of this issue. I do give myself leeway as to when I get an issue out but I don't think I have ever been this late , so my apologies.

I'm late because of a cross country move. I am now happily settled back in Chapel Hill, NC. I was lucky enough to get my old job back at UNC Hospitals! And even more exciting is that UNC is developing a feeding team so our kids can come and see a GI nurse practioner, speech/feeding therapist, and a dietician, all in one shot. I am very excited! More to come on that front. Thanks, Krisi Brackett

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Don't be a "Babies R Us" Therapist: Thinking past the bottle in the NICU

by Erin Sundseth Ross, Ph.D., CCC-SLP

Feeding the medically fragile infant requires knowledge beyond what is typically gained while in a graduate program, and most therapists gain this knowledge through continuing education offerings and mentoring. Most graduate programs offer coursework that spans the full spectrum of ages with whom therapists work. Many programs focus their pediatric programs around speech and language disorders, and their dysphagia education on the older child or adult. Few programs focus attention on the role of a therapist in the Neonatal Intensive Care Unit (NICU) or on the specific needs of the medically fragile infant.

Therapists tend to begin working with this population using the "tried and true" techniques applicable to the geriatric population, and quickly learn that the challenges seen while working with infants are different than those with adults. Rather than working with a motivated patient who wants to eat, infants interact based upon what feels good at that time. Infants are establishing their learned experiences with feeding; therefore, every feeding experience must be as positive as possible. While most infants discharge from the hospital taking full breast or bottle feedings, over time many infants display negative feeding behaviors and slow in their growth velocity. Kirkby and colleagues (2007) found that less than one percent of moderately preterm infants required supplemental tube feedings at the time of discharge from the initial NICU hospitalization (Kirkby, Greenspan et al. 2007), but over fifty percent of parents report problematic feeding be-

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Special Points of Interest:

- © Current information
- New products
- © Research and publications
- © Education

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Don't be a "Babies R Us" Therapist: Thinking past the bottle in the NICU by Erin Sundseth Ross, Ph.D., CCC-SLP

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haviors in children 18-24 months of age (Hawdon, Beauregard et al. 2000; Cerro, Zeunert et al. 2002). The focus of feeding in the NICU should be on enjoying the experience and interacting with parents, rather than on volume. When therapists seek continuing education to work effectively with this population, they begin to understand the unique needs of these medically fragile infants.

Infants require an expertise in the broader areas that contribute to successful feeding, which include an understanding of medical conditions that negatively influence physiologic stability, as well as sensory system development, gross/fine and oral motor development and nutrition. Feeding both in the NICU and in the young infant after discharge is influenced by factors in addition to swallowing; therapists must be knowledgeable about these factors that influence the ability and desire to eat, and consider the NICU setting as the foundation for later feeding development. Medically fragile infants often have instability in their respiratory and digestive systems that interfere with their transition to the extrauterine environment. The sensory system is undergoing rapid development in an environment that is often unpredictable and overwhelming. This input negatively influences the organization of the sensory system.

Parents of preterm infants report increased negative moods, decreased adaptability, decreased tolerance to sensory input, and increased overall difficulty in temperament when compared to parental reports of term infants (Langkamp, Kim et al. 1998). In addition to these physiologic and sensory factors, the NICU adds an additional complicating factor related to normal development of feeding skills. Infants are often asked to feed at a specific gestational age rather than based upon cues of readiness. Much like infants who begin walking between 10 and 15 months of age, infants in the NICU do not all begin to eat at the same exact age but rather within an interval of time. Therapists and caregivers must respect that normal variation in skill development will influence when a particular infant is able to initiate breast and bottle feeding.

In the NICU setting, therapists need to be aware of how to monitor normal development of feeding and identify which infants might need an assessment and intervention. There is a growing body of data to guide a therapist in monitoring normal developmental milestones during the acquisition of a mature, coordinated suck/swallow and breathe sequence. With additional training (such as that provided by the Newborn Individualized Development Care and Assessment Program, or NID-CAP) therapists may transition their role within the NICU to one of a collaborator who is available to support overall development of the infant, rather than a therapist who is consulted only when the infant has failed to transition to full oral feedings. There are several frameworks that assist the therapist in providing support for this normal development of feeding in the preterm infant as well as for early identification of infants who are not reaching specific milestones. One such framework is the Baby Regulated Organization of Systems and Sucking (BROSS; Ross & Browne, 2003). The BROSS is an eight-step progression that uses stability across physiologic, motor, and arousal (state) systems as well as observable feeding behaviors to monitor progression towards competent feeding. The healthy, preterm infant will progress up the BROSS steps, from stability in the bed to organized feeding with several patterns of suck/swallow and breathe that are described in the literature as normal development. The therapist can also identify those infants who are not progressing as expected and develop therapeutic interventions as needed to support movement up the steps and to establish safe, successful feeding.

Therapists need to consider the progression of feeding within the context of both individual variation and medical comorbidities that directly influence the time it takes

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to transition to oral feedings. Gastro-esophageal reflux (GERD) and respiratory disease negatively influence both the ability to initiate and transition to full oral feedings (Frakaloss, Burke et al. 1998; Gewolb and Vice 2006). Research consistently indicates the mean gestational age (GA) at which the majority of preterm infants reach full oral feedings is 36 to 37 weeks, despite the use of therapeutic interventions designed to speed the process in preterm infants. Three research groups have attempted various oral stimulation programs designed to accelerate the acquisition of full oral feeds, with all of them reporting a mean GA of 36 weeks for both groups that receive oral stimulation and those that receive no intervention (Fucile, Gisel et al. 2005; Boiron, Da Nobrega et al. 2007; Bragelien, Rokke et al. 2007). However, Simpson and colleagues found a wide variation in the GA at which infants reached full oral feedings when progression was based upon successfully taking a full feeding (Simpson, Schanler et al. 2002). Preterm infants should not be considered delayed simply because they lack a mature suck, swallow, and breathe pattern prior to term. The truly difficult task for the therapist is to identify atypical development in this population and provide interventions that are individualized to each infant.

Treatment techniques must consider development and go far beyond using a special bottle or nipple. The first priority of an infant is to maintain a safe airway, and adjusting flow rate by changing a bottle or nipple might be an appropriate intervention. However, the NICU therapist should have a firm grasp of what specific components of the bottle or nipple are underlying the decision to minimize negative experiences with feeding. Rather than thinking of a "quick fix" of a bottle, preterm infants often need additional adjustments and supports from the caregiver during a feeding to be successful. Caregiver contributions include attending to the physical feeding environment and position of the infant and adjusting the pacing of the feeding. Bottle selection is only one of many interventions that may support the preterm infant to successfully feed. There are a number of continuing education resources for therapist working in this setting, including the Fragile Infant Feeding Institute, the Early Feeding Skills Assessment workshops, and the Neonatal Oral Motor Assessment Scale certification.

Therapists working with infants and young children with feeding difficulties need to recognize that the child's skills (and skill deficits) influence the feeding development occurring across the first 2 years of life, and previous experiences influence the infant learning. For example, the gross motor skill of sitting supports the infant's transition to self-feeding. Similarly, fine motor skills like reaching and grasping support independent exploration of foods. The first major oral-motor transition occurs with the integration of the reflexively driven pattern of sucking and emergence of the volitional sucking pattern (around 3 months of age in the term infant). If feeding experiences have been aversive prior to this time period, the infant may choose to stop eating. The majority of infants worldwide begin to show growth faltering after 3 months of age (Shrimpton, Victora et al. 2001). Because infants and young children are learning new skills (vs. re-acquiring past skills as is the case when working with the geriatric population), therapists need to work within a holistic framework that assesses and treats all of these areas when considering feeding therapy approaches rather than adapting techniques from a geriatric population. Once therapists embrace the complexity of working with the medically fragile infant, the NICU and early infancy becomes a wonderfully rich, rewarding experience.

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- Boiron, M., L. Da Nobrega, et al. (2007). "Effects of oral stimulation and oral support on non-nutritive sucking and feeding performance in preterm infants." Dev Med Child Neurol 49(6): 439-44.
- Bragelien, R., W. Rokke, et al. (2007). "Stimulation of sucking and swallowing to promote oral feeding in premature infants." Acta Paediatr 96(10): 1430-2.
- Cerro, N., S. Zeunert, et al. (2002). "Eating behaviour of children 1.5-3.5 years born preterm: parents' perceptions." <u>J Paediatr Child Health</u> 38(1): 72-8.
- Frakaloss, G., G. Burke, et al. (1998). "Impact of gastroesophageal reflux on growth and hospital stay in premature infants." J Pediatr Gastroenterol Nutr 26(2): 146-50.
- Fucile, S., E. G. Gisel, et al. (2005). "Effect of an oral stimulation program on sucking skill maturation of preterm infants." <u>Dev Med Child Neurol</u> 47(3): 158-62.
- Gewolb, I. H. and F. L. Vice (2006). "Maturational changes in the rhythms, patterning, and coordination of respiration and swallow during feeding in preterm and term infants." <u>Dev Med Child</u> Neurol 48(7): 589-94.
- Hawdon, J. M., N. Beauregard, et al. (2000). "Identification of neonates at risk of developing feeding problems in infancy." Dev Med Child Neurol 42(4): 235-9.
- Kirkby, S., J. S. Greenspan, et al. (2007). "Clinical outcomes and cost of the moderately preterm infant." Adv Neonatal Care 7(2): 80-7.
- Langkamp, D. L., Y. Kim, et al. (1998). "Temperament of preterm infants at 4 months of age: maternal ratings and perceptions." <u>J Dev Behav Pediatr</u> 19(6): 391-6.
- Shrimpton, R., C. G. Victora, et al. (2001). "Worldwide timing of growth faltering: implications for nutritional interventions." Pediatrics 107(5): E75.
- Simpson, C., R. J. Schanler, et al. (2002). "Early introduction of oral feeding in preterm infants." Pediatrics 110(3): 517-22.

Editorial: Approaching feeding in different

settings... I recently moved, leaving a job doing early intervention and private practice feeding to go back to my old job, in



a large teaching children's hospital where we see all types of patients. Suddenly, I am back in a world of very sick infants and children with a variety of diagnoses and treatment plans. I mentioned to a colleague that I haven't written the work "tachypnea" so much in years!

It makes me realize how much I love all of the levels of feeding and swallowing intervention. Our inpatients are often sicker and dealing with other issues while we are working on safe and successful feeding. Hopefully, setting them on a good path upon discharge.

Our out-patients, early intervention, and home health patients tend to be more stable but present a different set of challenges. With these kiddos, we are working with a child's baseline and helping to make their lives and that of their caregivers better with improved eating skills. So no matter what setting you are in—feeding is challenging and rewarding!

Frequently Asked Questions (FAQs) About Feeding Problems in Children with Autism Spectrum Disorders By: Jennifer Twachtman-Reilly, M.S. CCC-SLP Autism and Developmental Disabilities Consultation Center, LLC

Associate Editor, Autism Spectrum Quarterly

As they enter feeding clinics with increasing regularity, children with autism spectrum disorders (ASD) present a challenge to those who specialize in feeding and swallowing. The unique constellation of feeding issues encountered in this population raises many questions about what to expect and how to address the mealtime experience of the child with ASD. Answers to three common questions are presented below, along with resources which the reader can utilize to gain additional information:

FAQ 1: Many children with ASD have chewing and swallowing skills that are either normal or at least functional for consumption of a variety of foods. What types of feeding problems do children with ASD typically face?

A: As research attention to feeding problems in children with ASD increases, the absence of reported dysphagia specific to swallowing and aspiration is more apparent. This suggests that if aspiration is present in children with ASD, it is the result of an additional medical condition (e.g. seizure disorder, genetic syndrome.) and not a result of autism (Twachtman-Reilly, Amaral, & Zebrowski, 2008). Field, Garland, and Williams (2003) in their audit of children who were evaluated at a feeding clinic, noted that children with ASD were less likely to have oral motor problems than children with other developmental disabilities.

Several studies have identified the nature of feeding problems in the majority of children with ASD to be that of food selectivity (Ahearn, et al., 2001; Field, et al., 2003; Schreck & Williams, 2006; Williams, Dalrymple, & Neal, 2000). A recent study by Matson, Fodstad, and Dempsey (2009) has found the following eating difficulties to be specifically associated with ASD: "(1) prefers food of a certain texture or smell; (2) will only eat certain foods; (3) eats things that are not meant to be eaten; (4) eats too quickly; and (5) eats too much." (p. 765). This represents an expansion from the more benign notion of "pickiness" that is a more well-known feature of feeding difficulties in children with ASD, to a greater recognition of the potential threat to health and safety that can be posed by the child's eating behavior. Thus, it is important for the clinician to be aware that the child's manner of eating can put him/her at risk for choking, even when swallowing skills are adequate.

FAQ 2: What makes the feeding difficulties of children with ASD so unique?

A: The feeding difficulties that children with ASD have are highly influenced by the symptoms that make ASD unique. Among the symptoms are executive function difficulties; anxiety; repetitive / ritualistic behavior; social and language impairments; and sensory processing difficulties. The contributions of these difficulties and how they can impact feeding are presented in Twachtman-Reilly, et al. (2008). Difficulties with anxiety and repetitive / ritualistic behavior warrant special attention here:

Anxiety has been found to commonly occur in children with ASD, however when it is associated with feeding, it is often different from the types of fears typically experienced by children with feeding difficulties (Twachtman-Reilly, et al., (2008). Evans, et al. (2005) found that children with ASD experience less fear of harm or injury, but higher numbers of "situation fears" (e.g. elevators) and/or medical fears. This may account for the presence of some risky eating be-

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haviors (e.g. eating too quickly), since a fear of choking may not be present. Likewise, there may be inexplicable fears of foods, food groups, utensils, etc. the source of which may be difficult to decipher.

Bowers (2002), through her survey of parents of children with ASD referred for feeding difficulties, noted that, "no parents expressed concern about growth. Parents only expressed concern about the management of the feeding occasion." (p. 142). The rituals that children with ASD typically develop regarding many aspects of their lives often extend to mealtime and feeding. The types of repetitive behaviors (RBs) specifically associated with ASD (Turner, 1999) have been identified in research regarding feeding difficulties in this population (Ahearn et al., 2001; Raiten & Massaro, 1986; Schreck, Williams, & Smith, 2004; Williams, et al., 2000; Williams, Gibbons, & Schreck, 2005). These include insistence on specific methods of food preparation and/or presentation; insistence on using specific utensils or cups; and inflexibility regarding food appearance (e.g. refusing to eat a cookie that is broken).

FAQ 3: How are these feeding difficulties treated?

A: The majority of research on the treatment of feeding difficulties in children with ASD consists of single case studies incorporating behavioral methodologies (a review was recently conducted by Matson & Fodstad, 2009). Approaches include varying food presentation, various reinforcement procedures, and backward chaining, among others. The reader is referred to the individual studies for more information regarding treatment methodology and effectiveness.

There are several therapeutic techniques that are well-established in the treatment of children with ASD that can be also utilized in the assessment and treatment of feeding disorders in this population. One such technique is the use of visual supports (Bopp, et al., 2004). For assessment, visually-based schedule systems can show the child what to expect during the assessment process and, most importantly, when the assessment will be completed. During treatment, visual systems are an effective way of defining task expectations such as the number of bites the child is expected to take, or the amount of time that a non-preferred food needs to stay on the child's plate. Specific examples are given in Twachtman-Reilly, et al. (2008).



In conclusion, as our understanding of the nature and prevalence of feeding difficulties in children with ASD grows, the calls for early screening of feeding difficulties in this population grow stronger (Matson & Fodstad, 2009; Matson, et al., 2009). Thus, it is important for clinicians to be prepared to see more and more families of children with ASD seeking the expertise of feeding specialists. Increased knowledge of the unique needs of this population will increase our ability to provide effective intervention that serves both child and family.

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References:

- Ahearn, W. H., Castine, T., Nault, K., & Green, G. (2001). An assessment of food acceptance in children with autism or pervasive developmental disorder-not otherwise specified. *Journal of Autism and Developmental Disorders*, 31 (5), 505-511.
- Bopp, K. D., Brown, K. E., & Mirenda, P. (2004). Speech-language pathologists' roles in the delivery of positive behavior support for individuals with developmental disabilities. *American Journal of Speech-Language Pathology*, 13(1), 5-19.
- Bowers, L. (2002). An audit of referrals of children with autistic spectrum disorder to the dietetic service. *Journal of Human Nutrition and Dietetics*, 15, 141-144.
- Evans, D., Canavera, K., Kleinpeter, F., Maccubbin, E., & Taga, K. (2005). The fears, phobias, and anxieties of children with autism spectrum disorders and Down syndrome: Comparisons with developmentally and chronologically age matched children. *Child Psychiatry and Human Development*, 36(1), 3-26.
- Field, D., Garland, M., & Williams, K. (2003). Correlates of specific childhood feeding problems. *Journal of Paediatric Child Health*, 39, 299-304.
- Matson, J. L. & Fodstad, J. C. (2009). The treatment of food selectivity and other feeding problems in children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 3(2), 455-461.
- Matson, J. L., Fodstad, J. C., & Dempsey, T. (2009). The relationship of children's feeding problems to core symptoms of autism and PDD-NOS. Research in Autism Spectrum Disorders, 3(3), 759-766.
- Raiten, D. J. & Massaro, T. (1986). Perspectives on the nutritional ecology of autistic children. *Journal of Autism and Developmental Disabilities*, 16(2), 133-143.
- Schreck, K. A. & Williams, K. (2006). Food preferences and factors influencing food selectivity for children with autism spectrum disorders. [Electronic version]. Research in Developmental Disabilities, 27(4), 353-363.
- Schreck, K. A., Williams, K., & Smith, A. F. (2004). A comparison of eating behaviors between children with and without autism. *Journal of Autism and Developmental Disorders*, 34(4), 433-438.
- Turner, M. (1999). Annotation: Repetitive behavior in autism: A review of psychological research. *Journal of Child Psychology & Psychiatry*, 40(6), 839-849.
- Twachtman-Reilly, J., Amaral, S. C., & Zebrowski, P. P. (2008). Addressing feeding disorders in children on the autism spectrum in school-based settings: Physiological and behavioral issues. *Language, Speech, and Hearing Services in Schools, 39*(2), 261-272.
- Williams, P. G., Dalrymple, N., & Neal, J. (2000). Eating habits of children with autism. *Pediatric Nursing, 26*(3), 259-264.
- Williams, K., Gibbons, B., & Schreck, K. (2005). Comparing selective eaters with and without developmental disabilities. Journal of Developmental and Physical Disabilities, 17(3), 299-309

Functional Abdominal Pain and Visceral Hyperalgesia: Why does my tummy hurt so much? www.complexchild.com

by Susan Agrawal

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In the past few years, doctors have begun to recognize the significance of ongoing gut pain that is seemingly without anatomical or infectious cause. Commonly grouped together under the heading of Functional Pain, this type of pain can be both chronic and debilitating to children, as well as puzzling to doctors. Functional Abdominal Pain, as defined by the AAP Subcommittee on Chronic Abdominal Pain in Children, is "Abdominal pain without demonstrable evidence of a pathologic condition, such as an anatomic, metabolic, infectious, inflammatory, or neoplastic disorder; functional abdominal pain may present with symptoms typical of functional dyspepsia, irritable bowel syndrome, abdominal migraine, or functional abdominal pain syndrome." While in many children, Functional Abdominal Pain is a minor inconvenience that often resolves with time or age, in others, it can severely limit the ability to participate in customary childhood activities like school and play, or even prevent a child from using the gut at all.

In the past, Functional Abdominal Pain was often associated with anxiety, behavioral problems, or other psychological symptoms. While children with abdominal pain are more likely to present with these psychological disorders, there are many children with no underlying psychological or behavioral issues who nonetheless experience significant and remarkable abdominal pain. The pathophysiology of this pain is not well understood, but involves the Enteric Nervous System, or the system of motor and sensory nerves that are present within the entire gut. Because of the vast complexity of neural connections within this network, the Enteric Nervous System is often called the "Little Brain."

Recently, many gastroenterologists have begun to realize that severe cases of Functional Abdominal Pain may actually be the result of Visceral Hyperalgesia. Visceral Hyperalgesia, which may also be called Visceral Hypersensitivity, is a term that simply means an individual has increased sensitivity to pain in the visceral system of internal organs like the stomach, intestines, or pancreas. Normally, when one eats or drinks, the stomach and intestines stretch to accommodate the meal with no discomfort whatsoever. But in a child with Visceral Hyperalgesia, the mere act of filling the stomach or intestine with a small amount of fluid or food triggers the nerves in the gut to respond as if a painful stimulus has been introduced. Studies on children with irritable bowel syndrome and recurrent abdominal pain have shown that the former group has a much lower threshold for pain in the intestines, while the latter group felt pain in the stomach at a lower threshold.2 If motor nerves are affected, a motility disorder develops, and when sensory nerves are affected, Visceral Hyperalgesia is often the result. It is common for both types of disorders to be present in tandem.

What is painless to most children feels excruciatingly painful to children with Visceral Hyperalgesia. Children with this diagnosis commonly have pain responses to one or more types of agents: pain due to digestive processes such as food entering the gut or liquid stretching the gut; significantly increased pain due to infections, viruses, or other external insults on the gut; and a pain response to psychological events such as anxiety or fear. In many children, all that is needed to cause pain is the introduction of food into the stomach and intestine. Once the pain signal has been turned on, the pain may persist for weeks, months, or years, or may come in intermittent cycles.

What causes Visceral Hyperalgesia? In many cases, it occurs after a virus, illness, or other external assault on the gut. The illness causes temporary damage to the mucus lining of the stomach and intestines, resulting in stomach pain. This pain then sensitizes the nerves in the stomach and/or intestines, causing them to be left "turned on" and hypersensitive to pain. Other gastrointestinal conditions such as pancreatitis, motility disorders, cyclic vomiting (abdominal migraine), or even severe reflux may also trigger Visceral Hyperalgesia. In some children, only one small area of the digestive tract is affected, while in others, most or all of the gut is impacted.

Symptoms of Visceral Hyperalgesia are vague and often very difficult to categorize. In many cases, Visceral Hyperalgesia is a diagnosis of exclusion, after all tests for organic or anatomical disorders have come back negative. All

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diagnosed children experience pain, but the pain may be localized, diffuse, sharp, dull, burning, intermittent, or constant.

Many children with severe Visceral Hyperalgesia also have other symptoms such as bloating, constipation, diarrhea, retching, or vomiting. This is especially the case when both the sensory and motor nerves of the gut are affected. In many children, pain triggers gastrointestinal symptoms like retching and vomiting, which in turn create even more pain and distress. These additional symptoms, coupled with pain, may be so severe that a feeding tube or even a central line must be placed for enteral or intravenous feedings. Many children with Visceral Hyperalgesia, especially post-infectious hypersensitivity, will recover in time with no treatment. Other children, especially those with underlying gut issues like pancreatitis or a motility disorder, may require substantial intervention to provide adequate nutrition and manage pain and additional gastrointestinal symptoms. In most cases, with adequate management by a pediatric gastroenterologist who specializes in motility issues or Functional Abdominal Pain, a plan to manage symptoms can be developed and the child will be able to live a relatively normal life.

Children with acute-onset Visceral Hyperalgesia may benefit from typical acute pain medications ranging from Motrin to Morphine. In general, children who need acute pain relief are given non-narcotic pain relievers such as Tylenol or Motrin, or pseudo-opiates like Tramadol, since narcotics and opiates disturb motility of the gut and may worsen gut function in the long run. Once Visceral Hyperalgesia has become more habitual, other pain medications may be more appropriate. Commonly used medications include tricyclic antidepressants, especially Amitriptyline (Elavil), Nortriptyline (Pamelor), and Imipramine (Tofranil). Medications to treat neuropathic pain have also proven helpful, especially Gabapentin (Neurontin) and its new cousin Pregabalin (Lyrica). Other possible medications include Nifedipine (Procardia); Dicyclomine (Bentyl), Alosetron (Lotronex) or Tegaserod (Zelnorm) for children with more intestinal issues; Ondansetron (Zofran) to prevent vomiting; Hyoscyamine (Levsin) for children with spasms; and other anticholinergic and anti-nausea medications. Older children, particularly those with concurrent psychological disorders, may benefit from behavioral therapy or consultation with a chronic pain psychologist. Some children may also improve by receiving continuous small feeds through a feeding tube, particularly feedings directly into the jejunum via a GJ or J tube. Children with extremely severe Visceral Hyperalgesia may need a central line and TPN (IV) feedings to allow total gut rest.

Visceral Hyperalgesia is a difficult condition to diagnosis, understand, and treat. But with proper treatment, most children can resume the normal activities of childhood. Many will even overcome their Visceral Hyperalgesia over a period of six to eighteen months. Success depends entirely on finding a pediatric gastroenterologist familiar with Visceral Hyperalgesia, its causes, symptoms, and treatment.

1 American Academy of Pediatrics Subcommittee on Chronic Abdominal Pain. Chronic Abdominal Pain in Children. *Pediatrics* 2005;Vol. 115 No. 3:812-815.

2 Di Lorenzo C, Youssef NN, Sigurdsson L, Scharff L, Griffiths J, Wald A. Visceral hyperalgesia in children with functional abdominal pain. *Pediatrics* 2001;Vol. 139 No. 6:838-843.

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Case by Case: Transition off of a G-tube

(some success and some setbacks)

Background: MP is an 11 month old adjusted age female whose medical history includes former 24 week prematurity, trach and ventilator dependence, and g-tube for all nutrition. Developmentally, MP was doing very well. She was crawling, mouthing non-food items, and vocalizing with a Passy-muir trach valve (PMTV). Cognitive skills were assumed to be age appropriate.

Evaluation: Summary of her eval included the following:

Oral-Motor: immature oral motor pattern, able to suck on pacifier and occasional tastes. Good handling of saliva.

Swallowing: Passed a MBSS.

Respiratory: History of prematurity, trach and vent dependence although she is beginning to wean off of the vent. No history of pneumonia, bronchitis, asthma, or congestion.

Gastrointestinal: Dependence on g-tube for all nutrition with good tolerance, regular bowel movements. No clinical signs of GER or discomfort.

Motor: MP is followed by PT. She sits well and is crawling and cruising.

Nutrition: Good weight gain, followed closely by pediatrician.

Behavior: Interested in mouthing toys and objects, not interested in eating.

Tube Feeding Schedule:

Day: 90 cc bolus of 24 cal Similar given over 1 hour on the pump

Night: 40 cc per hour for 10 hours.

Current Therapy: MP was getting weekly feeding therapy from home health focusing on oral stimulation and tastes on a spoon. MP reacted to this with gagging, refusal to open her mouth, and blocking with her hands. Her therapist, whose experience was with patients with adult neurogenic issues, contacted early intervention for assistance.

Goals: Our goal was to transition MP off of her g-tube and toward oral feeding. We first had to figure out why MP had no interest in eating.

Therapy trials:

<u>Dry spoon</u> - Because MP was rejecting oral stimulation and bites offered on a spoon, we decided to
take away the element of food. Our goal was to find a level MP could have success. We also wanted
to get active participation from MP by teaching her to open her mouth and accept the dry spoon followed by play and distraction.

Case by Case: Transition off of a G-tube

(some success and some setbacks)

Results: we had some success initially. MP opened and accepted up to 5 dry spoons in a row. However after 1 week she began refusing again.

2. <u>Sassy infatrainer cup</u>: Next we decided to try a sassy infatrainer cup. Our goal was to teach MP to accept tastes/sips followed by play. If we could get MP taking consistent volumes of her formula, we then would be able to directly reduce her tube feedings. Again, MP has some initial success taking 1/2—1 ounce. After 2 weeks, she began to refuse.

<u>Setback</u>: What we realized after discussion with MP's mother, was that they were also weaning her ventilator. She was doing well with the transition off of the vent but it was too much for MP to practice feeding as well. At this point we went back to a few dry spoons and dry cup trials until we felt she was stable with her respiratory system.

3. <u>Increase hunger cues/time with empty stomach</u> - After she weaned from the vent during the day, we worked with her LMD and manipulated her tube feeding schedule to allow her more time off of the tube. We increased hr night tube feeds to 45 and condensed her 4 bolus feeds into 3 initially. This allowed 5-6 hours off of the g-tube. We asked mom to offer oral tastes/small bites of homemade purees 2 times during that period. After about 2 weeks, she began accepting regular bites. As her volumes and calories became more consistent, we were able to decrease all of her day tube feeds. This took about 6 weeks.

As feeding became successful for her, she was able to take more volume. She also was eager to try new foods and often would reach for her sister's snacks. Interestingly, she transitioned easily to soft chewable foods. It is noted that we fed her with her PMTV on.

<u>Setback:</u> At 2 1/2 months in to our feeding progress, MP was changed to Pediasure. She became very bloated and constipated, stooling 1-2X/week. At this point, she began to refuse everything by mouth and mom was forced to use the tube more to maintain calorie needs.

We asked the LMD if we could change MP's formula to Complete pediatric (a toddler tube feeding formula that is typically well tolerated). After changing to complete, she was able to stool 1-2X/day. And was much happier.

4. <u>Oral feeding</u>— we had to start back with tastes and small bites on the spoon followed by play and distraction. We also asked her LMD to consider an appetite stimulant to help jumpstart her oral feeding again. It was very disappointing to Mom and the therapists when MP stopped eating. It illustrated the close connection between the mouth and the digestive tract. MP has an excellent prognosis for success, but the setback is very disappointing to all.

On the Research Front:

Jadcherla SR, Stoner E, Gupta A, Bates DG, Fernandez S, Di Lorenzo C, Linscheid T. <u>Evaluation and management of neonatal dyaphagia: impact of pharyngeal motility studies and multidisplinary feeding strategy</u>. J Pediatr Gastroenterol Nutr. 2009 Feb;48(2):186-92. PMID:19179881

The authors aims were to determine pharyngoesophageal motility correlates in neonates with dysphagia and the impact of multidisciplinary feeding strategy. The subjects underwent a swallow-integrated pharyngoesophageal motility assessment of basal and adaptive swallowing reflexes using a micromanometry catheter and pneumohydraulic water perfusion system. In conclusion, swallow-integrated esophageal motility studies permit prolonged evaluation of swallowing reflexes and responses to stimuli under controlled conditions at cribside. Manometry may be a better predictor than VSS in identifying patients who are likely to succeed in vigorous intervention programs.

Jadcherla SR, Vijayapal AS, Leuthner S. <u>Feeding abilities in neonates with congenital heart disease: a retrospective study.</u> J Perinatol. 2009 Feb;29(2):112-8. Epub 2008 Sep 25. PMID: 18818664

Objectives were to characterize the evolution of feeding milestones related to transition to oral feeding among infants with congenital heart defects (CHD), and to identify associated variables impacting the feeding abilities. Specifically, the authors differentiated the feeding characteristics in neonates with acyanotic vs cyanotic CHD. In conclusion, In contrast to neonates with the cyanotic CHD, cyanotic CHD group had significant delays with (a) feeding readiness, (b) successful gastric feeding, (c) oromotor readiness and (d) successful oromotor skills. Co-morbid factors that may directly influence the delay in feeding milestones include the (a) duration of respiratory support and (b) use of cardiopulmonary bypass. Delays in achieving maximum gavage and maximum nippling may suggest foregut dysmotility and oropharyngeal dysphagia.

Smith LP, Otto SE, Wagner KA, Chewaproug L, Jacobs IN, Zur KB. <u>Management of oral feeding in children undergoing airway reconstruction</u>. Laryngoscope. 2009 May;119(5):967-73. PMID: 19358199

Authors' objective was to systematically evaluate perioperative management of oral feeding in children undergoing airway reconstruction. They concluded that safe oral alimentation early in the postoperative period is possible with a rigorous multidisciplinary approach. To minimize complications, postoperative oral feeding should be initiated in conjunction with a speech pathologist.

Sonies BC, Cintas HL, Parks R, Miller J, Caggiano C, Gottshall SG, Gerber L. <u>Brief assessment of motor function: content validity and reliability of the oral motor scales.</u> Am J Phys Med Rehabil. 2009 Jun;88(6):464-72. PMID: 19454854

The Brief Assessment of Motor Function consists of five 0- to 10-point hierarchical scales designed for rapid assessment of gross, fine, and oral motor skills. They describe the development and evaluation of the two Brief Assessment of Motor Function Oral Motor Scales: Oral Motor Articulation and Oral Motor Deglutition. All items on the content validity questionnaire had average agreement scores that exceeded criteria, except two, which were not clearly worded; these were clarified. Interrater and intrarater reliability values were 0.997 and 0.986 for the Oral Motor Articulation Scale and 0.977 and 0.997 for the Oral Motor Deglutition Scale. Expert feedback and reliability procedures suggest that the Brief Assessment of Motor Function Oral Motor Articulation and Deglutition Scales represent the content that they are designed to assess and are reliable for rapid assessment of oral motor skills.

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