

Pediatric Feeding and Dysphagia Newsletter

Dear Fellow Feeders:

In this issue— we continue our 3-part series on behavioral feeding, explore the topic of sleep feeding and summarize current feeding workshops. I had to add 4 extra pages to cover all of the info, we have so much to choose from! As always we have a case, up to date research, and an editorial.

I have to apologize for the lateness of this issue, I think this is the first time in 9 years that the issue is late, please bear with me! Hope you enjoy it.

Krisi Brackett

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Part 3: A Behavioral Feeding Therapy Case Study on Randomizing Meals to Facilitate Intake

By Ben Y. Zimmerman, BS, MS Behavioral Psychology, Los Altos Feeding Clinic

email: pediatric_feeding@sbcglobal.net , www.pediatricfeeding.org

Michael was a 4-year-old child diagnosed with autism. He had an unremarkable medical history. Prior to coming to Los Altos Feeding Clinic he would only consume bottles of formula. He would drink 6-8 bottles per day of concentrated formula. He would not drink from other containers nor would he drink other liquids. He also did not consume any solids.

He was seen for four weeks in total. Treatment was three times per day, five days per week. The first week consisted of introducing solids to him. It was decided to use purees for two reasons. First, he had never chewed on a solid, which could make sessions dangerous because poorly chewed solids can be a choking hazard. Second, more trials can occur per session because time is not wasted on chewing. Four foods, chicken, green beans, macaroni and cheese, and applesauce, were randomized throughout the meals and week. Introducing solids consisted of presenting a bite, while simultaneously verbally prompting him to take a bite. Initially the bite was presented to the top lip until there was a mouth opening, and then the bite was deposited in the mouth. The bite would not be deposited in cases of gagging, coughing or vomiting, but were put in during all other openings. Each meal had a time cap of twenty-five minutes, and volume of ten ounces of food. The session would end when either the time cap had elapsed or the volume was consumed, whichever occurred first.

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Special Points of Interest:

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

Editorial assistance provided by Elizabeth Crais Ph.D. CCC SLP, Division of Speech and Hearing Sciences, UNC-Chapel Hill

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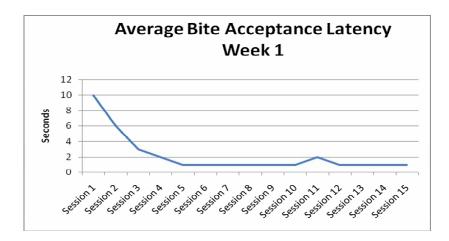
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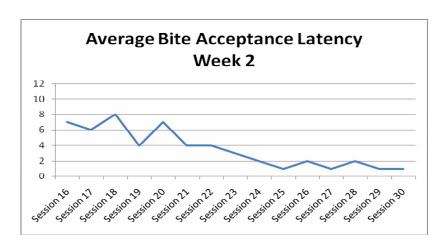
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The chart above shows how the time between presentation of food and the bite being taken decreased. During the first session, bites were taken an average of ten seconds after food presentation. By session three bites were taken on average after three seconds, and by session five they were stable at about one second.

Week two of treatment involved the introduction of new foods. Bites were presented with the same protocol as in week one. Four novel foods were presented in each session. Volumes of each food were held constant at three ounces each, including all food groups in the meal. Randomizing foods in this way, instead of focusing on one or just a few foods helped to generalize eating across all foods, as can be seen in the next graph.



There was a general trend in latencies dropping over time. By the tenth session of week two, latencies were stable at or near one second. This graph shows that eating was conditioned to occur at short latencies across all foods.

Generalizing meals to other settings serves the function of not only strengthening eating behaviors, but also ensuring that eating would take place across all settings (no matter the food), including the child's own home environment. Week three consisted of randomizing nine settings across the fifteen meals throughout the week. All other vari-

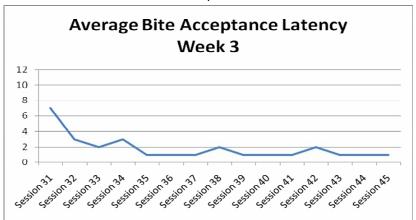
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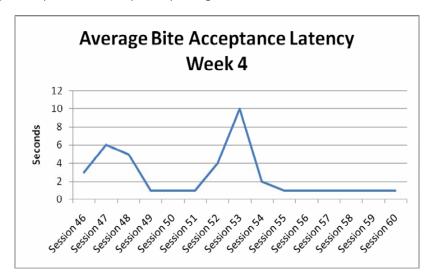
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ables were held constant, including randomizing the same foods used in week two. Settings included the park, playroom, different treatment rooms, hotel room, and hotel lobby.



There was an initial spike of refusal, which was followed by a sharp downward trend. By session 35, latencies were at or near one second.

Week four consisted of training primary caregiver to feed with random foods and random settings. This would ensure that feedings across settings and foods would not only take place in the context of the therapist, but also ensure that feedings take place with the primary caregiver.



There was a downward trend after session 47. Most meals thereafter were at one or two seconds, except for a spike in latency for sessions 52 and 53. Primary caregiver reported that eating continues at low latencies across foods and settings. This was reported four months subsequent to completion of treatment.

Data was collected by videotaping all sessions. Two data collectors independently took data while viewing video footage at separate times. Inter-observer reliability was measured at 86%.

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Facilitate Intake By Ben Y. Zimmerman, BS, MS Behavioral Psychology, Los Altos

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Los Altos Feeding Clinic specializes in the treatment of pediatric feeding disorders, serving children from the ages of 5 months to 13-years of age. All therapy is handled by a single Masters level or higher therapist, in a manner, which is customized for the particular child being treated. This allows for critical changes to be made sooner rather than later, which makes therapy quicker and more cost effective. Los Altos Feeding Clinic treats children from a behavioral standpoint, but also recognizes the strengths of using a multi-disciplinary approach. There are a dietician and an occupational therapist on staff. Please contact us at (650) 237-9111 for more information, or visit our website at www.pediatricfeeding.org.

There will be a seminar on pediatric feeding disorders in San Francisco, Ca on July 18-19, 2009. Please call (650) 237-9111 for more information or visit www.pediatricfeedingseminar.com.

Sleep Feeding: Observations and Insights By Jan Gambino, M.Ed.

Introduction

I became interested in sleep feeding when parents started leaving messages on The HealthCentral Network (www.healthcentral.com/acid-reflux) message boards, where I moderate discussions and write a weekly blog on all aspects of parenting an infant, child or teen with Gastroesophageal Reflux (GER) or Gastroesophageal Reflux Disease (GERD). Sleep feeding is the term used to describe a baby who needs to be drowsy or asleep to feed. Soon other parents were joining the discussion and in a short period of time, HealthCentral became SleepFeedingCentral with new parents typing in detailed descriptions of feeding their sleepy babies with reflux on a regular basis. As far as I can tell, the HealthCentral site has the largest repository of anecdotal information on sleep feeding that is available with approximately two dozen different, detailed sleep feeding stories, offering rich data. It is not clear if sleep feeding is on the rise or if the internet just provided the means for the information to be shared.

I need to disclose that I am neither a speech language pathologist nor a physician. I am a mom with extensive "on the job" training in caring for a child with GERD. I have provided support and information to hundreds of parents as a former associate director of a GERD patient support organization and lately as a freelance writer and author of a parents' guide to coping with GER and GERD. In addition, I am an educator with extensive experience in early intervention/preschool special education. The purpose of this article is to define sleep feeding, identify characteristics and offer some possible treatment/management strategies. As an advocate for parents and children, I will also present the parents point of view of sleep feeding and it's impact on the family.

What is Sleep Feeding?

Sleep feeding is the term used to describe feeding a drowsy or sleeping baby. Sleep feeding may be a normal process in the newborn period as many newborns begin a feeding in an alert state and gradually become drowsy and end the feeding in a light sleep. Suzanne Evans Morris, Ph.D., founder and director of New Visions (www.new-vis.com) stated, "When we begin to fall asleep, brain waves slow down and alert brain function decreases. The area of the brain that supports automatic, rhythmical sucking and swallowing remains active and strong at first,

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and then decreases as the baby moves to a deeper sleep." (1) In addition, research has shown that swallowing decreases during sleep compared to when awake.

As an infant matures, "a parent may use sleep feeding to encourage a young infant to sleep through the night or decrease the number of night feedings. This is a parent driven process with the parent offering the bottle or breast to her sleeping infant just before going to bed. It is hoped that this late night feeding, sometimes referred to as a 'top off feeding' will decrease night time hunger. A baby who is moving from a 24 hour feeding schedule to a daytime only schedule may adjust with short term sleep feeding during the transition "(2).

A review of the literature found no research on sleep feeding, however; there is extensive research on infant feeding and sleep patterns, feeding disorders and GER/GERD symptoms and treatments. In general, feeding disorders are thought to have multiple origins including medical, developmental and behavioral factors. It is not clear if sleep feeding is a feeding disorder, a symptom of reflux or something else.

Sleep Feeding and Reflux

An infant with GERD may experience difficulty with bottle feeding or nursing with typical symptoms including: pulling away, crying out and arching. It is thought that reflux pain and digestive discomfort may lead to feeding difficulties and the goal of treatment is to reduce pain and lessen other symptoms such as spit up and vomiting. However, it appears that some babies need to be drowsy or sleepy to accept the bottle or breast and exhibit the sleep feeding pattern as a reaction to pain. Sleep feeding probably stems from many causes, most notably the pain from GERD and also from a combination of sensory issues, food allergies/intolerances, dysphagia and behavior/learned patterns.

In an attempt to define sleep feeding, I would like to suggest the following definition:

"Sleep feeding is the term used to describe feeding a drowsy or sleeping infant due to digestive pain/discomfort caused by Gastroesophageal Reflux Disease (GERD) and related conditions." Sleep feeding is not harmful and may provide a short term feeding strategy while the underlying cause for the need for sleep feeding is determined.

Further, I propose a continuum of feeding problems associated with GER and GERD:

- **Level 1:** Happy Spitter: The happy spitter is a baby with GER. She nurses or drinks easily, then regurgitates a small amount or the entire meal without pain or discomfort.
- **Level 2:** Poor eating- As characterized by fussing, pulling on and off the breast or bottle and arching during a feeding. This is by far the most common pattern associated with GERD.
- Level 3: Feeding Aversion-A pattern of poor eating that persists, leading to weight loss or poor weight gain. The baby may experience sensory/swallowing symptoms such as: choking, gagging and painful swallowing.
- **Level 4:** Feeding Refusal/Feeding Strike-Is characterized by a baby who demonstrates poor eating and feeding aversion. In addition, he/she decides that feeding is just too painful and attempts to "fix" the problem by refusing all nourishment by mouth.

When a baby gets to the point of feeding refusal, there is a desperate attempt to offer nourishment. Parents have reportedly tried spoons, syringes, cups and even droppers to get a bit of liquid in. When all else fails, a parent will report these worrisome symptoms to the doctor or go to the emergency department. The doctor will evaluate the infant and rule out other causes for feeding refusal (illness, allergy, intolerance, and dysphagia). If a baby is dehydrated from prolonged feeding refusal, the infant may be hospitalized for observation, evaluation/testing or IV fluids. Often a parent is sent home with GER/GERD home care instructions such as holding upright after feeding, small, frequent meals, dietary changes and perhaps medication. Some infants are referred to a lac-

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tation specialist, speech language pathologist or occupational therapist for intervention. In most cases, the baby improves and begins taking nourishment again. Unfortunately, a small subset of babies continues to struggle with feeding and their desperate parents stumble upon sleep feeding.

Parents Perspective

As each and every meal results in digestive discomfort, the baby will resist and the parents will struggle to adapt the feedings and manipulate the environment to successfully nourish the baby.

Parents on the HealthCentral website often describe similar feeding experiences:

"I have to wait until he is asleep to feed him."

"When I lean her back in my arm to give her the bottle she cries."

"If I show him the bottle, he turns away and arches his back."

"When he is almost asleep, I can slip the bottle in his mouth for the feeding."

"It is getting harder and harder to feed him now that he naps less during the day. "

Parents experience a great deal of stress and anxiety about their inability to provide nourishment for their children. When they stumble upon sleep feeding, there is often a sense of relief. Within a short period of time, relief is replaced by new worries as sleep feeding becomes the only way their baby will eat. Parents often encounter questions and concerns from family members and friends who offer little understanding or support for the baby's feeding difficulties and need to eat while drowsy or asleep. Further, physicians may not understand the feeding pattern. If the baby is well nourished and growing from the vigilant efforts of a sensitive caretaker, the doctor may assume that there is not a medical or feeding problem. In addition, the doctor may conclude that the parent is having difficulty regulating the baby's sleep and feeding schedule and may instruct the parent to "teach" or "train" the baby to behave differently. This message conveys the feeling's of confusion and inadequacy as well as stress and anxiety. Unfortunately, some parents have felt compelled to "teach" the baby to eat and may withhold nourishment for hours at a time to induce hunger or force the baby to take a bottle, further strengthening the behavioral resistance to feeding.

I believe that sleep feeding emerges as a result of a sensitive, observant caretaker who carefully reads the baby's cues, observes subtle changes in behavior and instinctively helps the baby by swaddling, rocking, feeding in a quiet, dark place and even waiting until the baby is drowsy but not asleep to initiate feeding. Caretakers often report feelings of isolation as they must adjust their schedules around getting the baby to sleep or feeding the baby in a specific area so the baby will sleep feed. One mother reported that she needed to sit in a closet with the door closed to get her baby to eat. Other parents take turns staying up at night to feed their baby or set the alarm to wake up at intervals to initiate feedings so the baby can make up for missed feedings while awake during the day.

Parents and specifically mothers may experience feelings of sadness or inadequacy due to the struggles with sleep feeding. By day, the baby is in no distress and will smile, play and cuddle. Friends and family see a healthy, happy, well nourished baby. That is unless she is presented with a bottle whereupon the baby will turn away, cry, arch and become upset. One mother reported that her baby didn't want to be held because the baby thought the mother was going to initiate a feeding. Other babies cry out even when placed in a semi reclined position on the caretaker's lap. Many mothers have attempted nursing and quit with the belief that the baby "did not like my milk" or "my milk was causing so much pain".

The caregiver burden is significant when a baby will only eat when drowsy or asleep. Several parents have hired a nanny or asked a relative to live with the family to assist with running the household and offering support. The

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entire schedule is planned around naps, getting the baby to fall asleep or arranging the environment for optimal feeding (decreasing noise and distractions, darkening the room, turning off the TV and phone) to initiate feeding and then slowly getting the baby to suck on the bottle by rotating the bottle in the baby's mouth. The sleep feeding sessions are often long and only result in a small overall intake.

The connection and feelings of relief are enormous when a parent stumbles upon an online discussion such as the HealthCentral Network discussion board and discovers that he/she is not alone and he/she isn't the only person in the world with a baby who needs to sleep feed.

What we know

One member of the HealthCentral Network community, Archana Sudame took it upon herself to talk with as many caretakers of sleep feeding babies as possible and compiled information on the condition.

Based on her careful inquiries and from speaking to physicians and feeding therapists (speech language pathologists, occupational therapist), it seems that babies who sleep feed have the following characteristics:

- Sleep feeding occurs in otherwise healthy infants.
- Sleep feeding is an accepted short term feeding intervention for a baby with GERD as the medical team and feeding team explore treatment options and address the underlying pain/discomfort.
- Sleep feeding begins before 4 months of age.
- Prompt/effective medical treatment and reintroduction of awake feeding before 4-6 months may lead to resolution of sleep feeding.
- Untreated or unresolved sleep feeding that persists beyond 6 months of age may lead to a pattern of pain response/behavior that requires feeding therapy/intervention in addition to medical treatment.
- Sleep feeding usually resolves when an infant or toddler transitions to solids and learns to drink from a cup, usually between 9-15 months.

Treatment

The medical team needs to identify medical/sensory/behavioral conditions that have lead to or perpetuated sleep feeding. These include:

GER/GERD Milk and/or Soy Protein Intolerance

Food allergies/intolerances

Oral Motor/feeding disorders/delayed feeding skills

Illness

Behavior: learned behavior, reaction to pain. Constipation

Family: maternal depression, support, parenting skills.

Sensory Processing

The medical team needs to work with the family to diagnose and treat the underlying medical causes of sleep feeding. It appears that prompt evaluation and treatment of the underlying cause for the need to use sleep feeding may turn off the pain/discomfort and allow a young baby (under 4 months of age) to rapidly resolve a sleep feeding pattern. A lactation specialist or a feeding specialist may offer vital assistance to caregivers and help to reverse the sleep feeding pattern. A speech language pathologist may assist the doctor in assessing the feeding pattern to rule out an oral motor problem. A few babies need nasogastric or gastrostomy tube feedings to supplement sleep feeding and maintain weight gain. If the need for sleep feeding does not resolve despite aggressive medical treatment, referral to a feeding therapist or feeding clinic may be necessary. During the treatment, parents need ongoing, intensive support and reassurance from the medical team and referral to a patient support

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network.

Sleep feeding seems to run its course during the first year as the baby moves from bottle or breast to eating solids from a spoon and drinking from a cup. Early intervention to promote early acceptance of the spoon and cup may help a baby resolve sleep feeding before one year of age. Parents may need assistance to develop strategies to gradually help the baby move away from sleep feeding. Strategies may include: offering an empty bottle, spoon or cup for play and exploration, offering the bottle or breast at intervals while awake and gradually lessening the environmental modifications (from a darkened room to a dimly lit room). Some babies benefit from music, white nose, movement (rocking chair) and singing. Most babies gradually move toward cup and bottle drinking by day and require supplemental sleep feeding at night to ensure the proper intake of nutrients and fluids. Parents, doctors and feeding therapists all agree that sleep feeding babies present many challenges for intervention. The goal of intervention is often supportive as the infant gradually moves toward eating while awake.

Conclusion

There is a great need for research on sleep feeding to identify the causes, natural course and treatment / intervention. It is likely sleep feeding has several causes and may be multi factorial in nature. Food allergies, intolerances and infant GERD appear to be on the rise and may be a factor in causing/perpetuating sleep feeding. A recent study found that babies with symptoms of GERD often have dysphagia (3). Perhaps fear of choking or dysphagia causes some babies to literally shut down so they can manage to slowly and carefully suck and swallow.

As an early childhood special education teacher, I often deal with feeding issues since there is such a strong correlation between feeding disorders and developmental disorders. With the increase in Autism Spectrum Disorders (ASD) and the associated feeding and sensory issues, it is possible that some of the infants who sleep feed may be presenting with early sensory/processing problems that will later result in a diagnosis of ASD.

In the meantime, parents and doctors need to communicate effectively to describe and quantify feeding patterns that warrant further investigation and treatment. I spend a great deal of time helping parents to take a snapshot of a typical day by keeping a journal. A well organized list will help a sleepy, stressed parent with a fussy baby effectively communicate symptoms and concerns during the short time parents and doctors are together and may lead to a serious discussion about the feeding pattern. At the same time, physicians, lactation specialist and others who interact with new parents and newborns need to be aware of the signs and symptoms of GER; GERD and feeding patterns such as sleep feeding that are worrisome. If a parent report that the baby doesn't like to eat, turns away from the bottle or refuses the bottle, the medical team needs to make further inquiries and follow up to ensure the underlying problem is identified and addressed. It is discouraging that pediatricians still have limited knowledge of the NASPGHAN guidelines for evaluation and treatment of GER in infants and children despite efforts to increase awareness of the treatment guidelines(4).

The pendulum is swinging as it always does in medicine. In the past, infant GERD was believed to be undertreated and diagnosed. With the increased availability of new medications (specifically PPI's) for infants and children, there is a great deal of concern that all babies who present with GER symptoms are being administered strong medication for a non medical problem. A multi center, double blind placebo controlled trial of PPI's for the treatment of infant reflux demonstrated that half the babies treated with PPI's showed improvement. Surprisingly, half the babies in the control group also improved (5). While the new research greatly increases the medical team's ability to offer safe and effective treatment, it appears that physicians need access to this important information. There is a trend toward diagnosing and treating food allergies and intolerances in infants and the careful, short term use of GERD medications for some infants.

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I have found that parents and doctors have limited awareness of the role of the feeding specialist in caring for an infant with GERD, the need for sleep feeding and associated feeding issues. At the same time, not every community has a feeding clinic or SLP or OT who specializes in working with infant feeding disorders.

I recently published a book on parenting an infant or child with reflux. Reflux 101: A Parent's Guide to Gastroesophageal Reflux (Lulu, 2008) helps parents communicate with the medical/feeding team and gives parents the tools they need to implement the home care program that is vital to successful GER and GERD treatment. Often a busy doctor or a health clinic does not provide the time or follow up to ensure that the caregivers understand the home care plan and have the resources to carry out the plan. Parents need information, support and hope to take care of a baby in distress and help their baby grow and thrive. This is especially true for a baby with reflux who must be drowsy or asleep to take in nourishment.

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The author wishes to thank Archana Sudame and Suzanne Evan Morris, PhD for sharing their knowledge about sleep feeding for this article. Copyright 2009 Jan Gambino, www.refluxmom.com

Resources: Jan's Website: www.refluxmom.com

Jan's Blog: http://www.healthcentral.com/acid-reflux/c/96

Jan's Book: Reflux 101: A Parent's Guide to Gastroesophageal Reflux (Lulu, 2008)

Is available on www.lulu.com, www.target.com

Coming soon to www.barnesandnoble.com And in the UK at www.babyREFLUX.co.uk

About the author: Jan Gambino holds a B.S. degree in Special Education and Elementary Education from Boston University and a Masters degree in Early Childhood/ Special Education from the University of North Carolina at Chapel Hill. She has over 15 years experience working with infants and preschoolers with special needs. She received intense, on the job training in parenting a child with reflux following the birth of her youngest daughter with severe GERD and asthma. This led to her involvement in the Pediatric Adolescent Gastroesophageal Reflux Association (PAGER Association). Jan held the position of Associate Director of the PAGER Association for 6 years and has offered information and guidance to hundreds of parents worldwide who have contacted the association over the years. She has written numerous brochures and booklets about parenting a child with gastroesophageal reflux for the PAGER Association. She has published articles on pediatric reflux in Asthma and Allergy Today and Exceptional Parent Magazine. Jan writes a weekly blog on all aspects of parenting a child with reflux for The HealthCentral Network.

Jan lives in Maryland with her three children and two cats. She spends most of her time spewing helpful and graphic information about gastroesophageal reflux to friends and strangers or driving her van with vanity plates that read: GERDMOM.

Case by Case: Small intestine transplants by Patricia McMelleon, CCC-SLP

Background: The Children's Institute's Functional Feeding Program provides evaluation and treatment, on an inpatient and outpatient basis, for children with feeding difficulties. The inpatient feeding team provides intensive, daily treatment to address different types of feeding-related problems. Treatment can help children who:

- don't like to eat as a result of a medical condition
- avoid eating as a learned behavior
- don't eat enough food by mouth and, as a result, must continue with tube feeding
- do not progress to eating foods of various textures and food groups

History: MC is a 16 month female s/p small bowel transplant with g-tube. She was a full term baby who at 5 weeks of age developed a mid-gut volvulus secondary to malrotation. She had a small bowel resection which led to short gut syndrome and TPN dependency.

Feeding History: MC had prior exposure to baby food and accepted tastes on typical schedule but never accepted any measurable volumes. Post transplant (prior to admission to our facility) she was offered finger and soft foods. She took a few bites and also accepted 2-3 hulless popcorn and 2-3 ounces of water per day. She was willing to try foods but licked and spit them out. G-tube feeds were at 45ml/hr from 11p-7a and 95ml at 11am, 3pm and 7pm. She also received IV fluids at 40ml/hr from 11p-7a upon admission to our facility.

Oral Motor: She exhibited hypersensitivity in her tongue with increased gagging. She had no tongue lateralization, tilting or rolling. And she had decreased lip closure for clearing a spoon and containing a bolus. Her oral motor skills were decreased in terms of timing & coordination of chewing and forming a bolus. She exhibited oral hypersensitivity.

Intervention: OT started messy play and desensitization with puree and soft foods. Speech started intensive treatment $3\times$ /day for 5 days/week. I introduced a sipple cup starting with skim milk and working toward whole milk. I worked using a gradual progression, starting with touching, kisses, licks and eventually bites/drinks. I introduced smooth and pureed table foods via spoon using the same progression. Mom was brought into sessions after the first 1-2 weeks. By then MC was taking about an ounce of food and 1 ounce of drink per session. Mom was trained in the progression as well as some basic behavior (contracting if MC started to refuse) and oral motor exercises that targeted her OM deficits. The sensory, behavior and oral motor interventions that mom was trained in were used to help reshape meals and mealtime interactions with mom. They were also for mom to have in her "tool bag" once she was back home.

Outcome: At time of discharge (about 16 weeks total inpatient) MC went from being completely tube fed, IV fluids and less than 10% po intake to decreased oral hypersensitivity, tolerating 2-4 ounces of smooth/ puree table foods per meal, licks/tastes of new foods x10 per session, increased diet variety with 60ml new food in meals every 1 week and tolerating 1-3 ounces of liquids via sippie cup per meal. When you look at inpatient progress vs outpatient progress in the same 16 week period, I think the inpatient stay is definitely beneficial. The child receives therapy 2-3x per day. At this intensity it is easy to overcome the aversiveness and sensitivities and make-up lost experience with food through messy play, OT activities and oral motor interventions. The intensity allows us to immerse the child in food activities and experiences whereas outpatient would only see the child a few times per week. Our experience with outpatient courses is that it takes the child twice as long to overcome the aversiveness and sensitivities with so few structured encounters. The other piece of the puzzle is that often there is a psychosocial component to eating. The child has looked to the parent to "rescue" them from all the medical interventions they encounter and as a result when it comes time to work on something "hard" (food) the child will not work with the parent or will exhibit behaviors around food.

Case by Case: Small intestine transplants by Patricia McMelleon ,CCC-SLP

Discussion: MC's outcome was so good because mom started from the very beginning and kept on schedule "developmentally" introducing bottles, cups, food and liquids. Even though MC never took any volumes, mom kept exposing her to the foods. At every mealtime MC was always given a portion to play, smell, lick, taste or whatever she wanted to do with it. It is this pre-exposure prior to the transplant that is so important in normal development of the sensory system. It gives the child an important non-threatening and pleasant relationship with food. Early intervention can really help with just messy play and overall exposure to foods. So for those kids that you get on your caseload either pre-transplant or even post-transplant, there are many things that you can do to further their progress:

- Messy play
- Pretend play with pretend food and non food items
- Establish mealtime routines and structure
- Target normal oral motor development

Help parents to see opportunities when foods can be introduced, sensory areas can be addressed or oral motor skills can be targeted within normal every day routines/mealtimes

Remember that volume is not always the most important target, especially early on. The goal is to increase stamina and also to progress with developmental milestones that were missed or never achieved and have a direct or indirect impact on feeding skills.

Post transplant there are a few items to keep in mind:

• Enterovirus, adenovirus, increased output, rejection are the most common things that will "stall" progress with food acceptance and volumes.

High potassium and high sugar are 2 things that will cause increased output and possibly rejection. Be aware of the foods that are offered and stay away from or limit foods that are high in raw sugar and potassium. A dietician can really be an asset for helping you manage this aspect of recovery.

Terms:

<u>Adenovirus</u>- commonly causes respiratory illness but can also cause other illnesses such as gastroenteritits, conjunctivitis, cystitis and rash illness. Patients with compromised immune systems are especially susceptible.

<u>Enterovirus</u>- a virus found in respiratory secretions and stool. Commonly affect infants, children and adolescents.

<u>Stoma</u>- A stoma is an artificial opening to or from the intestine (which is also known as the gut or bowel) on the abdominal wall usually created by a surgeon.

Patricia McMelleon MA, CCC/-SLP, Senior SLP, Inpatient Functional Feeding Program The Hospital at The Children's Institute
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Workshop: Beckman Oral Motor Assessment & Intervention

Instructor: Debra Beckman SLP-CCC

More info: www.beckmanoralmotor.com

This is a summary of feeding workshops currently being offered. This is not an exclusive list by any means, also check out feeding programs and ADNANCE for offerings!

Brief summary: This is a two-day, hands-on intensive workshop. Participants will learn compensatory hands-on techniques for tonic bite, slow oral transit, tongue thrust, and gag. The participants will practice over 50 specific intervention strategies for improving facial muscle function for eating and speech. Additional topics of discussion may include: goal writing, diet texture progression, tube to oral issues, adaptive mealtime utensils, oral hygiene issues, medication administration issues, oral function for individuals with trachs, facilitating improved articulation through oral motor techniques, research issues, videofluroscopy issues for motorically involved individuals, and additional topics of importance as determined by the participants.

Workshop: Becoming a Mealtime Partner

Instructor: Suzanne Evans Morris, Ph.D. (New Visions) More info: New Visions website - http://new-vis.com/ws/p-mealpartner.htm

Brief summary: The New Visions Mealtime Partners Workshop, "Becoming a Mealtime Partner" is designed for a small group of 10 parents and professionals who wish to understand and expand their child's feeding challenges within a broader context of mealtimes. This customized learning experience provides the tools for each participant to create a family-focused program to develop the child's inner-directed eating and drinking skills through a foundation of comfort, confidence, and competence. 3 days.

Workshop: Evaluation, Treatment & Management Across the Lifespan: focus on Treatment Using Videofluoroscopy

Instructors: Joan Arvedson PhD, CCC-SLP, BC-NCD, BRS-S, ASHA Fellow & Jeri Logemann, PhD, CCC-SLP, BRS-S

More info: www.nss-nrs.com, (888) 337-3866 or email info@nss-nrs.com

Brief summary: Conference provides experience in reading anatomy and physiology of normal and abnormal swallowing from x-ray swallow studies of infants, children, and adults. Varied etiologies will be covered. Current evidence based treatment and management options for all diagnostic groups will be discussed using VFSS as integral part of treatment planning. Similarities and differences in swallow anatomy and physiology of children and adults will be explained to help participants gain confidence when evaluating and treating a variety of age groups. For SLP's only, 2 days.

Workshop: Feeding Frustrations: Innovative Strategies that Work

Instructors: Angela Mansolillo, MA/CCC-SLP More info: www.educationresourcesinc.com, (508) 359-6533 or (800) 487-6530

Brief summary: Discuss the interplay between oral-motor, gastrointestinal, and respiratory systems. Select and perform appropriate pediatric assessments in clinical and instrumental evaluation. Develop and implement holistic treatment plans which include nutrition, behavior management and normalization of sensation. Determine the most effective intervention based Diet, Surgical Interventions on research evidence and the pros and cons of various oral motor treatment approaches. Identify the ethical considerations specific to the pediatric population.

Workshop: Feeding the Whole Child: A Mealtimes Approach

Instructor: Suzanne Evans Morris, Ph.D. (New Visions) More info: http://new-vis.com/ws/p-mealpartner.htm

Brief summary: The workshop explores some of the roadblocks that limit the development of eating skills and comfort in order to help children return to their natural desire to be part of mealtimes. Strategies designed to increase feeding skills within the mealtime environment are discussed. An emphasis is placed on supporting positive change through comfort, confidence, and competence. The workshop will address the feeding and mealtime issues of children who eat and drink by mouth as well as those who receive their nutrition through a feeding tube. 2 days.

Workshop: The Get Permission Approach to Sensory Mealtime Challenges

Instructors: Marsha Dunn Klein MED., OTR/L More info: www.mealtimenotions.com

Brief summary: "Get Permission" is an approach to mealtimes and feeding treatment based on the foundation of trust in a feeding relationship. It supports children who have sensory mealtime challenges in moving forward with mealtime goals with trust, enjoyment, and confidence. It follows the child's lead with creative and sensitive mealtime treatment strategies. The purpose of this 2 day relationship-based workshop is to provide treatment and family support strategies for children with sensory mealtime challenges. Its focus is to help children find enjoyment and confidence in the sensory aspects of mealtimes. We look at complicated sensory challenges for children who are worried about the sensory aspects of feeding, those who have had limited or scary oral sensory experiences, those who are fed by tube, have visual impairments or are on the autism spectrum. It supports an approach of getting oral sensory permission as a foundation of trust for change. Case studies will be reviewed and discussed.

Workshop: Integrated Treatment of Feeding, Speech and Mouth Function In Pediatrics

Instructor: Diane Bahr, CCC-SLP More info: 702-845-0642; Email: agesandstages@cox.net; or www.agesandstages.net

Brief summary: Finally, a course that is equally valuable for OT's and SLP's. This workshop helps therapists and others choose appropriate treatment techniques for pediatric clients with a variety of disabilities (e.g., prematurity, autism, Down syndrome, cerebral palsy). It is particularly helpful for OT's and SLP's who work on teams and need to divide responsibility when addressing feeding, eating, drinking, oral hygiene, orofacial myofunctional speech, and motor planning concerns. Many of the techniques learned by participants are "good practices" that can be safely taught to care providers. Group interactive experiences and DVD demonstrations provide many opportunities for clinical problem solving.

Workshop: Mealtime Miseries: Management of Complex Feeding Disorders

Instructors: Carol Elliott, OTR/L & Elizabeth Clawson, PhD, LCP More info: http://www.educationresourcesinc.com

Brief summary: How does feeding, a process so integral to the child's health and well-being, go awry? The focus of this 2 day course is on a transdisciplinary (TR-eat) model integrating oral motor therapy techniques and behavioral management for the treatment of complex feeding problems. It will cover innovative strategies, using video case examples, to address oral aversion, food refusal, poor transition onto solid foods, texture grading, learning to chew, self feeding and feeding difficulties related to autism and picky eaters. It is relevant for infants and children through school age. This course is packed with practical solutions and hands on techniques that will empower you with new treatment ideas for your most complex patients. These interventions are systematic and evidence based with research suppoting outcomes. This course is appropriate for clinicians with all level of experience.

Workshop: NICU and Early Intervention Feeding

Instructors: Erin Sundseth Ross, Ph.D., CCC-SLP More info: www.educationresourcesinc.com or Erin.Ross@ucdenver.edu

Brief summary: This 2-day feeding workshop is designed for those who work with infants in, or just discharged from, a NICU. Two days of practical information from a developmental specialist will help practitioners to increase their knowledge about factors that impact successful oral feeding. While breastfeeding supports are discussed, the focus is on bottle-feeding. The presenter will include information on preterm and medically fragile term infants. Strategies to facilitate infant abilities will be emphasized. The role of the caregiver during interactions to support the acquisition of appropriate feeding skills is a strong component of this training. The presenter values a multi-disciplinary supportive team in the NICU and after discharge to Early Intervention follow-up services. The focus is on supporting the infants through these transitions, rather than on specific oral-motor techniques that would be used with infants who have known dysfunctional feeding problems. A holistic approach integrating the medical fragility of these infants is emphasized.

Workshop: NICU FEEDING FRUSTRATIONS: A Cue-Based Approach for the Entire Team

Instructors: Catherine Shaker MS/CCC-SLP, BRS-S, Suzanne Thoyre RN, PhD

More info: Pediatric Resources Inc., (414) 431-8104, pediatricresources@tds.net

Brief summary: Finally, a common language about feeding for your NICU team! Learn the key components of an effective cue-based approach that is essential to collaborative feeding practice. Review research about the preterm's feeding skill acquisition, the role of experience, growth, dynamic systems theory, and feeding outcomes after intensive care. View engagement, physiologic stability, oral-motor, swallowing, coordination of s-s-b based on infant cues via videotaped feedings. Gain confidence using the Early Feeding Skills Assessment Tool, which profiles skills that are not evident, emerging or established. Use that info to plan individualized interventions that work for the entire team. Learn the components of a gentle feeding approach that can be adapted minute by minute. Interdisciplinary group problem-solving that addresses some of the common problems encountered by team members. Receive training in use of the Early Feeding Skills Checklist and several take home resources for continued learning and implementation into their NICU. A common sense approach to feeding and a new direction for your team!

Workshop: NICU INTERVENTION: Swallowing/Feeding Issues in the Nursery and After Discharge

Instructors: Catherine Shaker MS/CCC-SLP, BRS-S More info: (414) 431-8104, pediatricresources@tds.net

Brief summary: Cutting-edge 2 day course. Essential evidence-based information for managing the complex swallowing and feeding needs of preterm and sick term infants in the NICU and after discharge. Functional problem-solving approach to assessment and treatment, including a broad range of interventions. Case studies, videos of neonates feeding, and swallow studies enhance learning. Attendees often say this is "The best NICU course you can find!"

Workshop: Oral Motor, Feeding/Swallowing and Respiratory Coordination in Children with Neuromotor Involvement.

Instructors: Rona Alexander PhD, CCC-SLP More info: www.educationresourcesinc.com, (508) 359-6533 or (800) 487-6530

Brief summary: This 3 day workshop will focus on what members of a multidisciplinary team need to know about the assessment and treatment of infants and children with neuromotor impairments and challenges to their oral motor, feeding/swallowing, and respiratory coordination function. Special emphasis will be placed on understanding a variety of areas that may be influencing a child's feeding and swallowing function; the impact that body alignment, active postural control, and sensory factors have on oral motor function; and suggestions for the incorporation of strategies focusing on these areas into treatment programming. Treatment planning and strat- egies to improve cheeks/lips, tongue, jaw, and rib cage unction will be discussed. Group lab sessions, audio visual materials, and patient demonstration sessions will be used to provide problem-solving experiences to assist participants in integrating information.

Workshop: Pediatric Feeding Disorders: A Medical, Motor, & Behavior Approach

Instructor: Krisi Brackett MS SLP/CCC More info: feedingnews@earthlink.net, call 801-599-8250, motivationsceu.com

Brief summary: This course focuses on a medical motor, & behavior approach to feeding intervention. Day 1 is our medical day. We focus on an intervention philosophy, an in depth look at medical issues that interfere with successful feeding practice such as reflux and motility disorders as well as covering nutrition basics. Day 2 covers evaluation techniques with live demos and intervention strategies. Therapy strategies are covered in detail including how to set up a behavioral feeding program, how to break a suckle pattern, how to teach a child to chew, how to teach cup drinking and transition off of a feeding tube. Information is research based. Course format is lecture, dvd's and live kids. Suitable for all pediatric feeding across settings; hospital, early intervention, out-patient and schools!

Workshop: Pediatric Feeding the Big Picture 1:Sensory, Motor and Behavioral Issues with Feeding Disorders

Instructors: Jennifer Meyer MA, CCC-SLP More info and dates:www.ciaoseminars.com or Call 888-909-2426

Brief summary: In this one day intermediate course you will learn how to work together to evaluate and choose different techniques and modalities in light of the specific needs of the child and the knowledge-base, roles, and scope of each discipline.

Workshop: Pediatric Feeding the Big Picture 2: Medical and Family Dynamics Issues with Feeding Disorders

Instructors: Jennifer Meyer MA, CCC-SLP More info: www.ciaoseminars.com or Call 888-909-2426.

Brief summary: In this one day advanced, follow-up course, using case studies and group discussion we will delve into two more causes: Medical Problems and glitches in the Family Dynamics.

Workshop: PEDIATRIC SWALLOWING AND FEEDING: The Essentials

Instructors: Catherine Shaker MS/CCC-SLP, BRS-S, Theresa Gager MS/CCC-SLP

More info: (414) 431-8104, pediatricresources@tds.net

Brief summary: Comprehensive two day seminar covering assessment and treatment of swallowing/oral-motor/feeding from a problem-solving perspective. Neonates through school age. Current approaches, case studies. Videos to enhance learning. Essential skills for pediatric practice and problem-solving complex cases. Rated "excellent" in feedback received from both highly experienced therapists and new grads! Multiple learning levels.

Workshop: PEDIATRIC VIDEOFLUOROSCOPIC SWALLOW STUDIES: From Physiology to Analysis

Instructors: Catherine Shaker MS/CCC-SLP, BRS-S More info: (414) 431-8104, pediatricresources@tds.net

Brief summary: Extensive information for conducting and interpreting pediatric swallow studies. Procedures in preparation for and during the study. Recommendations and optional treatment modalities will be highlighted. A pediatric history and report format will be provided. Videos of normal swallowing and typical radiographic swallowing problems will be shown and discussed. Feedback in 2007 noted "phenomenal up-to-date compendium of information and peds videos!" See for yourself!

Workshop:Pediatric videofluoroscopic Swallow Studies: Interpretation, Decision Making, and Treatment.

Instructors: Joan Arvedson PhD, CCC-SLP, BC-NCD, BRS-S, ASHA Fellow **More info:** www.nss-nrs.com , (888) 337-3866 or email info@nss-nrs.com

Brief summary: 1 day course, for more info email address above.

Workshop: SOS Approach to Feeding Workshops

Instructors: Kay Toomey Ph.D. More info: call 303-759-5316 or email jburton2523@yahoo.com

Brief summary: This 3 day workshop consists of 2 components = 1). a 2.5 day BASIC training on the use of the SOS Approach to Feeding program + 2). a half day consisting of 2 Special Population talks regarding special feeding issues specific to certain diagnoses (eg. GERD, G-tubes or Food Sensitivities/Allergies) Advanced Workshops: 3 to 4 times a year, a 4th day of Advanced topics (from 2 hours to 4 hours) workshops are added on to the end of the 3 Day Basic Workshop. They address how to adapt the SOS Approach to Feeding basic program to specific populations of children (eg. children with Autism; Infants/Toddlers 6 months to 16 months; School Aged children), or how to hone one's feeding skills with the SOS Approach (eg. Tools in Your Pantry; Parents as Partners; Setting up a Feeding Clinic).

Workshop: Special Topics in Pediatric Feeding and Swallowing: Intermediate- Advanced

Instructors: Joan Arvedson PhD, CCC-SLP, BC-NCD, BRS-S, ASHA Fellow More info: www.educationresourcesinc.com, (508) 359-6533 or (800) 487-6530

Brief summary: Participants will learn an effective problem solving approach for a variety of etiologies that underlie dysphagia and will be armed with intervention strategies that address complex issues for medically fragile infants and children, picky eaters, children with gastroesophageal reflux, children with g-tubes and others. 2 days.

Workshop: TRACHEOSTOMY AND SWALLOWING Pediatrics to Adults

Instructors: Michele Clouse MA/CCC-SLP More info: (414) 431-8104, pediatricresources@tds.net

Brief summary: Want to hear the essentials about trachs from an expert? Learn about the unique challenges faced by the tracheostomized child and adult in relation to swallowing. Focus on how the "plumbing" of the swallow can be altered by a tracheotomy. Consider clinical and instrumental assessment, speaking valve use, & a variety of interventions to provide appropriate, safe and effective means to oral nutrition. You will experience a hands-on learning experience with tracheostomy tubes, and speaking valves. This seminar has been sold out every year! "The hands-on with tubes and problem-solving were immediately applicable. Now I feel like I can manage trachs!" said an attendee.

Workshop: Treating Complex Pediatric Feeding Disorders: Treating the Whole Child

Instructor: Mary C. Tarbell, M.Ed, CCC-SLP More info: www.educationresourcesinc.com, (508) 359-6533 or (800) 487-6530

Brief summary: Children with complex feeding aversions/disorders in hospital, school and private practice settings present a challenge for clinicians. In this workshop, clinicians

will learn a successful comprehensive holistic evaluation of these complex problems including those encountered by children with structural issues, cardiac issues, prematurity, Autism, Syndromes, GI issues, sensory integration disorders, Down Syndrome. Day 2 will focus on a holistic treatment approach for common feeding disorders that are characteristic of many of these children including tube dependency, lack of autonomy, rigid eating patterns, inability to regulate their own hunger/satiety and difficulty transitioning to table foods. In addition to innovative effective treatment techniques, participants will learn the criteria to determine what intensity of therapy is warranted. Many case studies with videos will be used to illustrate the complex nature of these children. While it is geared to the 2-5 year old child, the material applies to infants through school age children.

Editorial: Evaluating a child with a feeding tube...

I recommend watching a tube feeding as part of your evaluation or if you don't have time during the initial eval, make it part of one of your therapy sessions. You're watching for the child's comfort level with his or her tube feeding. When children are uncomfortable with tube feedings, it can manifest in many ways such as vomiting, retching or dry heaving, arching, crying, hyper-salivation, eyes tearing, gagging, etc. If the child is uncomfortable, every time their stomach is filled, it will be hard to teach them to want eat by mouth. Help the child with gut comfort by working closely with the medical team.



On the Research Front:

Coulthard H, Harris G, Emmett P. Delayed introduction of lumpy foods to children during the complementary feeding period affects child's food acceptance and feeding at 7 years of age. Matern Child Nutr. 2009 Jan;5(1):75-85. h.l.coulthard.1@bham.ac.uk

This study followed children who had been introduced to lumpy solids (chewy foods) at different ages, and to assess their dietary intake and feeding difficulties at 7 years of age. Children were divided into 3 groups based on the age at which they were first introduced to 'lumpy' solids: 12.1% were introduced before 6 months of age, 69.8% were introduced between 6 and 9 months of age and 18.1% were introduced after 9 months. Children introduced to lumpy solids after the age of 9 months ate less of many of the food groups at seven years, including all 10 categories of fruit and vegetables, than those introduced to lumpy foods between 6-9 months. In addition they were reported as having significantly more feeding problems at seven years. The long-term feeding problems and reduced consumption of important food groups such as fruit and vegetables in children who are introduced to lumpy foods after the age of 9 months is a cause for concern. Health professionals must encourage the progression from purees and exposure to important food groups. PMID: 19161546

Chao HC, Chen SY, Chen CC, Chang KW, Kong MS, Lai MW, Chiu CH. The impact of constipation on growth in children. Pediatr Res. 2008 Sep;64(3):308-11.

The observation on the impact of constipation on nutritional and growth status in healthy children has never been reported. During a 4-y period, we evaluated the consequence of constipation on growth in children. A marked increase of appetite was significantly correlated with better gain on height and weight after treatment. We conclude that chronic constipation may retard growth status in children, and a long-term medication for constipation in children appears beneficial to their growth status. PMID: 18414138

Suiter DM, Leder SB, Karas DE. The 3-ounce (90-cc) water swallow challenge: a screening test for children with suspected oropharyngeal dysphagia. Otolaryngol Head Neck Surg. 2009 Feb;140(2):187-90.

Authors concluded that if the 3-ounce water swallow challenge is passed, not only thin liquids but diet recommendations with puree and solid food consistencies can be made without the need for further instrumental dysphagia assessment. The 3-ounce water swallow challenge has been shown to be a clinically useful screening test for oropharyngeal dysphagia in children.PMID: 19201286

Duca AP, Dantas RO, Rodrigues AA, Sawamura R. Evaluation of swallowing in children with vomiting after feeding. Dysphagia. 2008 Jun;23(2):177-82. Epub 2007 Nov 1

Vomiting after feeding is a symptom of gastroesophageal reflux (GER) and of eosinophilic esophagitis (EE), which are considered to be a cause of infant feeding disorder. The objective of the present study was to evaluate swallowing in children with feeding disorder manifested by vomiting after feeding. Authors concluded that there was no difference in the timing of oral swallowing transit, pharyngeal swallowing transit, or pharyngeal clearance between patients and controls. We conclude that children with vomiting after feeding may have difficulties in accepting feeding, although they have no alteration of oral and pharyngeal phases of swallowing.PMID: 17973160

Ferrini FR, Marba ST, Gavião MB. Oral conditions in very low and extremely low birth weight children. J Dent Child (Chic). 2008 Sep-Dec;75(3):235-42.

The purpose of this study was to evaluate the oral conditions in very low birth weight (VLBW) and extremely low birth weight (ELBW) children. Results indicated that very low birth weight and extremely low birth weight were indicators of enamel defects and contributed to an increase in non-nutritive suction habits. Early preventive and interceptive measures to avoid future severe problems is recommended. PMID: 19040808

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