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**The Speech Pathologist's Role with
the Pediatric Intestinal Rehabilitation
Population, presented in partnership
with Cincinnati Children's**

**Presenters: Abby Mathews M.A. CCC-SLP
Luann Stevens M.A. CCC-SLP**

Moderated by:

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The Speech Pathologist's Role with the Pediatric Intestinal Rehabilitation Population

Presented by:

Abby Mathews M.A. CCC-SLP

Luann Stevens M.A. CCC-SLP

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Learning Objectives

After this course, participants will be able to:

- Define diagnoses that result in short bowel syndrome.
- Describe the goal of speech pathology treatment in the intestinal rehabilitation population.
- List 2-3 therapy techniques applicable to oral aversion treatment.

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The Population We Serve

- Cincinnati Children's Intestinal Care Center (CICC)
- Patients with Short Gut Syndrome and Intestinal Failure resulting from a variety of disorders
- Ages - Newborn to Teen
- Former Premies
- Children who are attempting to transition from paraenteral to enteral nutrition or to fully oral nutrition

Short Gut Syndrome

- Occurs when a large portion of the intestines does not work normally
- When a large section has been surgically removed or baby is born with abnormal intestines
- Complications
 - Failure to Thrive
 - Dehydration
 - Central Line Infections (can be fatal)
 - Vitamin Deficiencies
 - Liver Disease

Intestinal Failure

- “Inability to sustain adequate nutritional, electrolyte or hydrational status in the absence of specialized nutritional support” (Buchman, 2006)
- The largest single group of patients who received home TPN were those with short bowel syndrome – 35% (Buchman, 2006)
- Approximately half of the short bowel patients who initially require TPN can be weaned off TPN successfully in optimal settings. (Buchman, 2006)

Intestinal Rehabilitation

- Goal is to help the body to absorb all of the nutrients it needs to grow
- Intestinal Rehab uses strategies and therapies designed to make the bowel work better – including nutrition support, nutritional rehabilitation, medical management or restorative surgery

Goals of Intestinal Rehab

- To transition off of TPN
- Tolerate enteral feeds
- Maximize oral interest

Related Diagnoses

- Gastroschisis
- Necrotizing Enterocolitis (NEC)
- Omphalocele and OEIS
- Hirschprung's Disease
- Auto Immune Bowel Disease / Enteropathy
- Malrotation/ Volvulus
- Motility Disorders/ Pseudobstruction

Gastroschisis

- A birth defect that occurs between the 4th and 8th week of pregnancy when an opening forms in the baby's abdominal wall. The bowel pushes through the opening and continues to develop outside of the body.
- The bowel is unprotected in the amniotic fluid so there is a possibility that it can become irritated, swollen, damaged or not develop correctly.

Gastroschisis

- Not usually associated with other malformations
- 1 in 2000 births
- Repair is necessary immediately as bowel can't survive outside of the body
- Hospitalization for 30-50 days, or more
- Initially fed with IV nutrition

Gastroschisis Repair

- Primary - if baby has a small amount of bowel outside the body, may be repaired in one surgery
- If the baby has a large amount of bowel, several surgeries may be needed.
 - Takes place over days, up to 2 weeks
 - A silo is placed around the bowel.
 - The silo is tightened daily and some of the bowel is pushed inside.
 - When the bowel is inside, the silo is removed and the belly is surgically closed.

Example images of procedure:

https://medlineplus.gov/ency/presentations/100023_1.htm

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Necrotizing Enterocolitis (NEC)

- Illness which may damage the walls of the abdomen. If NEC continues to spread, a hole in the abdomen wall may occur that allows bacteria to leak out and cause an infection.
- Is the most common gastrointestinal emergency in the NICU.
- Happens most often in babies born premature, but can also happen in full term babies.
- Occurs in 10% of all babies born weighing less than 3 ½ pounds.

Baby with History of NEC

Omphalocele

- Occurs when the bowel, liver, and sometimes other organs remain outside the belly in a sac
- The belly organs may be injured and the belly does not grow to its normal size. The belly may be too small to hold all of the organs
- Sac protects organs, so repair may be later
- Can have subsequent bowel obstructions
- Can be part of OEIS complex (omphalocele-exstrophy-imperforate anus-spinal defects)

Omphalocele Repair

- Sample images can be found here:

https://medlineplus.gov/ency/presentations/100033_4.htm

Hirschprung's Disease

- Occurs when some of the nerve cells that are normal present in the wall of the intestine do not form properly during fetal development.
- Stool can back up causing either a partial or complete bowel obstruction
- A bacterial infection can develop in the digestive tract. This can sometimes lead to a bowel perforation.

Treatment Team Members

- Gastroenterologists
- Nutrition
- Nurse managers
- Speech Language Pathologists
- Behavioral Medicine
- Social Work
- Occupational Therapy
- Physical Therapy
- Discharge Planning Coordinator

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VIDEO – Dr. Conrad Cole Intro

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Dr. Cole Quotes

- “My name is Dr. Conrad Cole. I am a professor of Pediatrics at the University of Cincinnati College of Medicine and Cincinnati Children’s Hospital Medical Center. I am also the medical director for the Intestinal Rehab Program Comprehensive Nutrition Center at Cincinnati Children’s Hospital Medical Center.”

Dr. Cole Quotes

- “So our intestinal rehab program basically manages patients on chronic paraenteral nutrition. These are patients who do not grow well if all they have to use is their gastrointestinal tract. So the clinic helps with working them through the process of chronic management of TPN and also slowly introducing them to some degree of tube feeds. But also encourage them and working with them so that they would also start eating by mouth.”

VIDEO – Dr. Conrad Cole Role of SLP

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Dr. Cole Quotes

- “Well the speech therapist definitely help in our patients because these patients have been chronically ill they have missed the critical points of introducing feeds. And so having therapies to working with them enables them to at least start reintroducing feeds by mouth.”

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Dr. Cole Quotes

- “Expectations is that for the therapies to evaluate the patient appropriately. Then teach, work with the child and the parents so that we can identify what the appropriate steps are so that these kids can progress in their oral feeding skills.”

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Dr. Cole Quotes

- “Yea I think having therapies if possible...would be working closely with the providers for these patients who are on chronic TPN is very important. Because you can make recommendations, you can slowly decrease TPN and increase enteral feeds but without the appropriate skills sets the child takes forever or would never get on to any amount of oral feeds.”

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Dr. Cole Quotes

- “These kids are chronically deprived of you know the oral stimulation cause they are sick and in the hospital. The first thing you want to do is save their life which we do with TPN but slowly we need to be able to get them off TPN which means they need to be on tube feeds and stay on tube feeds and we also want to try to decrease the tube feeds which means that we have to work on their oral skills.”

Role of SLP

- Provide ongoing evaluation of feeding skills and swallowing ability
- Work with RD and MD to formulate a therapy stimulation or oral feeding plan

Non Nutritive Stimulation (Infant)

- Creating positive oral experiences
- Increasing comfort with touch to face and mouth
- Practice to increase oral skills
- Tolerating sensory aspects
- Oral care
- Provide education to caregivers regarding patient specific cues and recommendations

Non Nutritive Stimulation (Older Child)

- Learn about foods in a non threatening way
- Interact with foods and utensils for play and exploration
- Oral Care
- Caregiver education

Oral Feeding Plan

- Practice with limited volumes to increase oral skills
- Increase child's interest in taking tastes
- Feeding recommendations

Enteral Feeding

- “Refers to any method of feeding that uses the gastrointestinal tract to deliver part or all of a person's caloric requirements. It can include a normal oral diet, the use of liquid supplements or delivery of part or all of the daily requirements by use of a tube.” (Kirby, 2011)

Feeding Tubes

- Nasogastric Feeds (NG)- Nutrition is delivered via flexible tube placed into nose, down through the esophagus into the stomach
- Nasojejunal (NJ)- Nutrition is delivered via flexible tube from nose into esophagus to the small bowel
- Gastrostomy tube (G tube)- Surgically placed tube into the stomach
- Jejunostomy tube (J tube)- Surgically placed tube into the small bowel
- GJ tube- Surgically placed tube into the stomach and small bowel

Parenteral Nutrition

- “Parenteral nutrition refers to the delivery of calories and nutrients into a vein. This could be as simple as carbohydrate calories delivered as simple sugar in an intravenous solution or all of the required nutrients could be delivered including carbohydrate, protein, fat, electrolytes (for example sodium and potassium), vitamins and trace elements (for example copper and zinc).” (Kirby, 2011)

Schedules

- Continuous Feeds
 - NJ or GJ feeds can only be given continuously
 - Windows- present oral feeding trials, just before end of the window
- Bolus – Entire feed given in smaller amount of time.
 - Give oral trial prior to feed administration
- PO/Gavage
 - Allow to first take oral feed as interested and able then give remainder through the tube

Example Integrated Bolus/Oral Schedule

Scheduled Meals and Bolus Feeds:

9:30am: Breakfast	10:00am: Bolus
12:30am: Lunch	1:00pm: Bolus
5:30pm: Dinner	6:00pm: Bolus

- Seat Gracelyn in her highchair or booster seat
- Offer 2-3 age appropriate food items each meal.
- Offer small bites of food on her tray at a time, so Gracelyn is not overwhelmed.
- If she refuses, pushes away foods or becomes fussy, take a break. Allow her to play while staying in highchair. After a few minutes, reoffer food. If she refuses ask her if she is "all done" and then stop the meal.
- Keep mealtime a fun and enjoyable time for Gracelyn.
- Mealtime should be kept to 30 minutes.
- **Avoid feeding in between scheduled meals.**

Thank you and call with questions.

Growing Through Knowing Cincinnati Children's

Daily Food Guide for Infants 0 – 12 Months with Intestinal Failure

Food Group	Foods	Daily Amounts	Serving Size
Newborn – 4 months Your baby shows skills of rooting, sucking, and swallowing.			
Milk	Breastmilk Formula	On demand 6 – 12 feedings	2 – 6 oz.
4 – 6 months Now your baby is holding his or her head up and only needs a little support when sitting up. This is a good time to start solids. Start with single ingredients meats/proteins first.			
Milk	Breastmilk Formula	On demand 4 – 6 feedings	6 – 8 oz. 6 – 8 oz.
Protein	Strained/pureed chicken, beef, turkey, pork, beans, tofu	Offer	1-2 tbsp.
Vegetable	Strained/pureed vegetables	Offer	1-2 tbsp.
Grain	Iron fortified baby cereal *Avoid probiotic cereals	2 servings	1 – 2 tbsp.
Fruit	Avoid fruit and fruit juices. These can cause increased stool.		
6 – 8 months Your baby should have good head and body control, and be interested in putting toys in his/her mouth.			
Milk	Breastmilk Formula	On demand 4 – 5 feedings	6 – 8 oz. 6 – 8 oz.
Protein	Ground chicken, beef, turkey, pork, beans, tofu	2 servings	2 – 3 tbsp.
Vegetable	Mashed vegetables	2 servings	2 – 3 tbsp.
Grain	Iron fortified baby cereal Bread/crackers/cereal	2 servings Offer	2 – 4 tbsp.
8 – 12 months To help work on development, your baby can start self-feeding small, soft finger foods.			
Milk	Breastmilk Formula	On demand 3 – 4 feedings	6 – 8 oz. 3 – 4 tbsp.
Protein	Ground chicken, beef, turkey, pork, beans, tofu, eggs	2 servings	
Vegetable	Mashed/soft vegetables	2-3 servings	3-4 oz.
Grain	Iron fortified baby cereal Bread/cracker/cereal	2 servings Offer	3 – 4 tbsp. ½ slice

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Nutrition for Intestinal Rehabilitation

FOOD GROUP	SUGGESTED SERVING	FOODS TO INCLUDE	FOODS TO AVOID
Grains 4-6 servings/day	½ piece bread ½ cup hot cereal, pasta, rice, potato ½ cup cold cereal 3 crackers	Low sugar cereals, breads, crackers, rice and pastas Choose whole grains and high fiber foods	Sugar coated and sweetened cereals, frosted or sweetened muffins, rolls, doughnuts
Vegetables 3 servings/day	¼ - 1/3 cup cooked or canned 1/3 cup raw	All vegetables allowed. Add butter, cheese or gravies	Any with sweetened sauces Vegetable juice blends such as V8 splash
Fruit 3-4 servings/day	½ cup cooked/ canned ½ medium size fresh	Fresh fruits, unsweetened canned fruits	No juices or sweetened canned fruit (i.e. in heavy syrup)
Meat and Meat Substitutes 3-4 servings/day	1 ounce cooked 1 Tbsp peanut butter ½ cup beans ½ egg	All allowed including peanut butter, eggs, dry beans and nuts	None
Dairy 2-3 servings/day	4-6 ounces milk 1/3-1/2 cup yogurt ½ ounce of cheese ½ cup cottage cheese	Whole milk, cheeses, unsweetened yogurt	Low fat milk, ice cream, ice milk, low fat yogurt
Fats	If child is underweight, increasing fat in diet can be beneficial	All allowed. Butter, margarine, salad oils, cream cheese, salad dressings, bacon, etc. Canola oil, corn oil, flaxseed, mayonnaise, nuts safflower and olive oil	High saturated fat foods such as fried and fast foods.
Desserts and sweets			All sugar, sweets, desserts and candy including "sugar-free" foods and artificial sweeteners
Seasonings and condiments		All spices, garlic, ketchup, herbs mustard, salt and pepper	Baubeque sauce, duck sauce, hoisey and sweet and sour sauce
Drinks		Water, formula and whole milk, low calorie sports drinks	Juices, regular soda, fruit drinks, Kool-Aid, coffee, tea

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Beside Feeding Evaluation

- Obtain thorough history
 - Previous speech records
 - Outpatient
 - Previous admissions
 - Results of previous instrumental assessments
 - VSS
 - Fees
 - Current and previous feeding experiences

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Special Considerations for IR Evaluation

- How is patient currently fed?
 - All oral, all enteral, TPN, or combination
- Reason for Referral
 - Clear for tastes/therapy
 - Oral motor concerns
 - Advance feeding
 - Behavioral Feeding
 - Swallow safety
- Is there a safe/stable feeding plan?

Results of Evaluation

- Oral skills
- Oral aversion
- Swallowing function
- Enteral Feeding Tolerance
- Developmental level
- Social circumstances

Results from Evaluation: Oral Motor

- Oral Motor Dysfunction:
 - Impaired secretion management
 - Difficulty coordinating to manage liquid and/or form bolus
 - Anterior loss of food or liquid
 - Lack of tongue lateralization
 - Decreased oral clearance
 - Decreased efficiency extracting formula from nipple
 - Decreased lip closure/tongue cupping on pacifier
 - Difficulty biting
 - Immature/ineffective chewing

Results from Evaluation: Oral Aversion

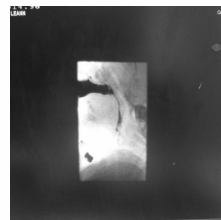
- Oral Aversion:
 - Hypersensitivity to input in/around oral cavity
 - Difficulty with oral care/ toothbrushing
 - Refusal of certain textures
 - Gagging at sight, smell, or taste of food
 - Avoidance of eating environment
 - Spitting food out
 - Turning/Pushing away from food, utensils, feeder
 - Consistently crying during feeding attempts
 - Not opening mouth upon presentation of spoon

Results from Evaluation: Aspiration

- Coughing
- Increased congestion during/immediately after feeding
- Throat Clearing
- Wet, gurgly vocal quality
- Increased work of breathing
- Refusal of previously accepted food items

Results of Evaluation: Aspiration

- Results of instrumental assessments
 - Material entering trachea
 - Amount
 - Consistency of aspirated material
 - Effect of therapeutic techniques
 - Presence of cough response to attempt to clear
 - Can patient produce volitional cough
 - Volitional voicing to assess vocal quality
 - Fatigue Component



Follow Up of the Evaluation

- Recommendations
 - Must call the medical team
 - Diet order
 - With whom/volume/frequency should patient feed
 - Must be in conjunction with RD plan
 - If recommending ANY modifications a feeding plan should be formulated, reviewed with RN and family, and posted in room
 - If needed obtain order for instrumental assessment/ discuss timing
 - Developmental orders

Results of Evaluation: Language

- Language skills are informally assessed during initial evaluation
 - Auditory Comprehension
 - Expressive Language
 - Pragmatics
 - Speech
 - Cognitive Play Skills
- Effects of prolonged hospitalization

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Feeding Therapy Progression- Baby

- Non Nutritive Stimulation
- Tastes
- Bottle feeds
- Introduction to Purees
- Introduction to Soft Solids
- Solids

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Non Nutritive Stimulation

- Presentation of pacifiers, textured teething toys, nuk brush, duo spoon, vibrating toys/tooth brush
- Begin on outside of body and progress to face and mouth
 - Hands, arms, cheeks, lips, tongue, buccal cavity
- ALWAYS respect cues. Do not be forceful in any way.
 - With signs of distress, give short break and return to previously tolerated stimulation activity. If refusal again, transition to play based.

Non Nutritive Stimulation

- Use dry spoon to increase tolerance of caregiver bringing spoon to mouth
- Allow baby a second spoon to encourage self presentation
- Pretend play feeding baby dolls or toys
- Praise all positive interactions

VIDEO – JV spoon

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Tastes

- Appropriate for patients medically approved to begin transition to oral purees or formula OR patients with limited tolerance
- Offer small no volume tastes (breast milk, formula, baby food) on nipple, spoon, teething toys, hands, or pacifier*
 - Use caution with the pacifier. If baby enjoys pacifier and does not like tastes, keep pacifier as a “safe” object.

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VIDEO – PW infant tastes on pacifier

Infant Bottle Feeds

- Allowance varies dependent on enteral feeding rate
- Often start with small volumes as baby works up on feeds (5 mLs)
- May be allowed hourly rate or equivalent during window
- Typically begin with slow flow nipple and pacing

VIDEO – MJ Accepting Bottle

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Introduction of Purees

- Must be showing developmental readiness, not specifically attached to age
- Typically start with pureed meats, then vegetables
- No fruits, because of sugar content
- Can offer on spoons, teething toys, hands, lid
- Encourage tactile play seated in high chair for support

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Introduction of Purees

- Provide a second spoon for baby to dip and bring to mouth
- Avoid use of stage 3 baby foods due to mixed consistency of puree and lumps
- After smooth puree is tolerated, can offer mashed soft solids that are same texture throughout
 - Avocado, sweet potato, cooked carrot

VIDEO – JV refuse puree on spoon

VIDEO – JV calm with toy

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Solids

- Child must demonstrate interest and oral skills
- Allow child to participate in sensory play
 - Explore by touching, smelling, licking, tasting, taking bites and putting in “all done bowl”, taking bites and swallowing
- Introduce a variety of tastes, flavors, textures

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VIDEO – CM stirring ranch

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VIDEO – CM mom feeding mac and cheese spoons

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Liquids

- Ideally, child will accept formula by mouth. This is what we will offer first
- Most can have G2 Gatorade after age 1
- Medical team usually prefers to limit the amount of water and ice
- Some children will accept spoons of broth
- Avoid sugary drinks as this can increase stool output
- Use dips if preferred to bridge foods



Feeding Therapy Techniques

- Learn about and interact with foods in a non threatening way
- Offer small bites
- Offer small portions
- Offer preferred and non preferred food items
- Implement “all done” bowl
- If child can tolerate, offer variety of textures

Feeding Therapy Techniques

- Talking about food
 - Classifying regarding shape, color, texture
- Make grocery lists, help shopping, discuss ingredients, assist with meal preparation
- Food rating (scale of 1-10)

Feeding Therapy Techniques

- Food log to track trends; give suggestions to increase food repertoire
- Homework assignments to assist with carry-over
- Incorporating child into family meals and holiday celebrations
- Reward system/ meal contract
- Refer to behavioral medicine

VIDEO – T.B. “all done”

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Feeding Therapy Techniques

- Textures/Food groups
- Setting up meal time environment
 - Same time, same place, same expectations, establishing routine
- Parent Education
 - Subtle cues
 - Oral motor

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VIDEO – CM mom model French fry dip in ketchup

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Feeding Plan

- Goal for therapist, family and staff to offer consistent oral experiences
- Educate regarding goal of treatment – typically quality over quantity
- Describe patient specific cues of interest and refusal
- Example plan

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Nutritive Oral Stimulation Plan

Name: Adalayne
Date: 10/10/16
Speech Therapist: Abby Mathews
Occupational Therapist: Laura Kohus

These activities are focused on creating positive experiences and being comfortable with touch to various areas of the face and mouth as well as introducing tastes. If any of these activities appear discomforting or make Addie upset please discontinue.

Setting an appropriate environment for stimulation is very important.

1. Addie should be calm and alert for oral-stim and tastes
2. Provide tastes 1-2 times daily.
3. Addie is allowed tastes of formula. (Please ask your nurse to get Addie's proper formula for tastes)
4. **Addie can have dipped tastes of formula, but she does not have to take all of it.**
5. An upright supported position is best for tastes (Bumbo Seat, High chair)
6. If she is fussy, please stop.

Stimulation Techniques.

1. Slowly present spoon, cup, or bottle toys to Addie's mouth.
2. If tolerated place a small taste of formula on these objects.
3. Addie is allowed to have small tastes at this time. The medical team does not want her to have any volume.
4. Wait for her to manage the taste in her mouth before giving another bite.
5. If she gets upset, makes a face, or lets you know she is done by turning her head away. Please take a break before offering again.
6. Give Addie praise by clapping or verbal praise each time she takes a taste or brings objects to her mouth.

Good Luck! Please feel free to contact with any questions!

Feeding Plan

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Language Therapy

- Developmental stimulation and speech/language therapy are an important component of long term treatment
- If admission is longer, 2 weeks or more, developmental intervention is initiated

Outpatient

- During admission, outpatient therapy services in home area will be arranged.
 - Early Intervention or Private (encourage families to ask primary care physician to ask for recommendations in hometown area)
- Followed through CCHMC Intestinal Rehab Clinic by speech therapist
- Can coordinate with home therapist

Case Study- P.W.

- CHARGE
- G-tube
- Short gut secondary to NEC
- Tracheostomy
- Currently on 16 hour feeds overnight
- 37 cm left of bowel

VIDEO – PW cheerios, feeding Dr. Cole

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Research

- Enteral Nutrition in Children with Short-Bowel Syndrome: Current Evidence and Recommendations for the Clinician
 - Presents overview of published data on feeding strategies in children with short bowel syndrome (Oliman, 2010.)

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- Recommendations:
 - Enteral nutrition should be initiated as soon as possible.
 - Should be administered in continuous manner.
 - Breast milk or standard formula is recommended
 - Bottle feeding should be started as soon as possible (Olieman, 2010).

Research

- Pediatric Feeding Disorders: Effectiveness of Multidisciplinary Inpatient Treatment of Gastrostomy-Tube Dependent Children (Cornwell, 2010).
 - Retrospective chart review of 40 g-tube fed patients with co-occurring medical conditions
 - Pre and post-treatment measures
 - Significant difference from admission to discharge for both oral intake and G-tube dependency

Research

- More research needs to be completed on this demographic!!!

Questions

Resource



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 Division of Speech-Language Pathology



Learn More

Link: <https://viablesynergy.wufoo.com/forms/s3q62e1k51n5v/>

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Resources

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