Eating is pleasurable…but not for all

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Personal disclaimer

- No financial relationships in this field
- This talk may not reflect the views and positions of BCM or TCH
- Imperfect knowledge as regards world’s publications/internet information
Objectives

- Participants will be able to list 4 signs/symptoms of concerns pointing to a potential diagnosis of abnormal oral motor skills
- Participants will be able to list 3 patterns of abnormal eating and their potential nutritional ramifications among children with autism spectrum disorders
Where we are in 2018

- No training specifically in children with neurodevelopmental delays
- All nutrition or GI pathologies in children with ASD and neurocognitive delays, but high likelihood of increased disease severity by the time of diagnosis
- Parents have various sources of information: internet, therapists, and other parents
- Families feel dismissed by medical providers
Our Goal

- Achieve nutrient goals in least restrictive form
- Concept of least restrictive
  - Involves safety
  - Involves social aspects of eating
How do parents view all this?

- Parents want their children to be able to eat like the rest of the family
- Gastrostomy tube seen as personal failure
- Parents seek the least restrictive option
- Parents may also believe that their child’s neurological problems may be the result of foods consumed
Relevant Client Features

- +/- prematurity
- Abnormal eating skills
- Communication deficits
- Gross and fine motor delays
- Disturbances in sleep
Brief review of feeding phases

- Pre-oral phase: client recognition of hunger and ability to communicate to caregiver

- Oral:
  - Infancy: suck swallow coordination
  - Later in infancy: bite, chew, propel bolus

- Pharyngeal
  - Involuntary phase when respiration briefly ceases
  - Bolus then propelled into esophagus

- Esophageal: involuntary contractions move bolus into the stomach
Parts of the mouth and neck involved in swallowing

- Tongue
- Pharynx (throat)
- Larynx (voice box)
- Esophagus (food channel)
- Trachea (windpipe)
Difficulties noted by feeder

- Cough/choke/gag
- Excessive time to eat
- Pocketing food in cheeks
- Swallowing foods whole
- Wet breathing sounds when eating
Effectors of Food and Nutrient intake

- Selectivity in food choices (behavior vs neurosensory)
  - Appearance
  - Odor
  - Texture
  - Brand

- Oral/pharyngeal motor delays
  - Delayed oral motor skills
  - Oral Hypersensitivity to texture
  - Inability to protect the airway

- Abdominal distension/gassiness

- Based on clinical or fluoroscopic evaluation: Need for alternative feeding methods HOWEVER how do these feeding methods impact oral feeding??
  - Nasogastric feeding
  - Gastrostomy feeding
  - GJ feeding
The special case of children with autism spectrum disorders

- Can be extremely selective about color, texture, even brands of foods accepted
  - The beige diet
  - The crispy diet
  - The ‘no chew diet’
  - The liquid diet
  - Extreme selectivity <10 items accepted

- Ability to ‘hold out’ for accepted items, even to the point of dehydration

- Contrast with obsession with foods in mouth, overeating

- May, however, be socially acceptable feeders, consuming any item caregiver provides
All disease begins in the gut

Hippocrates

Importance of GI Health

- All disease begins in the Gut
  - Hippocrates, the father of modern medicine

- Gut has constant contact with food
- Physical barrier of defense against bacteria, viruses, etc.
- The greatest amount (90%) of the "brain chemical" serotonin is found in the GI tract
- Largest part of the immune system (70%) found in the gut
- Vitamins/minerals absorbed in the gut are cofactors for enzyme reactions, metabolism, conversion of nutrients and fats
- Amino acids (absorbed from protein digestion) are precursors for neurotransmitters
Gluten free, casein free diet

- Based on research of abnormal metabolites in urine of children with ASD done in the 1970s
- Bans all wheat, rye, oats, barley, dairy products
- Reported improvement in 2/3 children--self reported
GF/CF diet

- Reasons for trying: guilt imposed by other parents, sense that med science has nothing else to offer
- NOT an endorsement
But what’s the science?

- Cochrane review 2008—only 2 double blind studies, sample #10 and #15, no benefit on objective behavioral scores
- recent Rochester study double blind placebo controlled challenge study in 14 children 3-5yrs old, followed for 30wks—no change in stools, behavior, or ASD symptoms (Hyman SL: J Autism Dev Disord (2016) 46:205)
- Does supplementation with gluten and casein change symptoms?
What are the complications?

- Reported decrease in Bone mineral density by 19%
- Diets low in calcium, vitamin D, protein, folate, B vitamins
- AAP guidelines suggest need for vigilance to protein, fiber, iron, D and Ca content of foods child accepts
- Pragmatic limitations
  - Cost
  - Difficulty of complex diet—Playdough, limited multivitamin sources
  - Lack of palatability
Feeding issues

- Parental concerns:
  - Eat like us
  - Enjoy eating
  - Fewer meltdowns

- Medical concern:
  - Nutritional adequacy
Approaches to Selectivity: the issues

- Restricted interest in food, poor appetite, poor recognition of hunger
- Focus on detail—ie brand
- Fear of new
- Insensitivity to peer pressure at meal/snack times
- Heightened sensation—smell, taste, texture (oral feel)
- Aversive behaviors at mealtimes—are they truly behaviors?
  - Choke
  - Gag
  - spit
Feeding therapy

- Know your client—functional level, sensitivities, motivators
- The ‘nevers’:
  - Trickery
  - Starvation
  - Force feeding
- Baby steps approach
  - Choose good sensory fit food item
  - Include on table @ meal or snack
  - Item on plate
  - Touch, smell
  - Bring item to lips
  - Touch item with tongue
  - Finally taste, and repeat daily for several weeks
Alternative feeding strategies

- Food chaining—know your client
  - Developed by SLP

- Transition from current beverage to nutritionally complete drink, then working on expanding solids in school, therapy

- Cyproheptadine trial???
Nutritional concerns

- Evaluate typical daily intake for several key nutrients:
  - The beige diet eaters: ascorbate
  - The non-meat eaters: iron
  - The solely milk drinkers: iron, ascorbate

- Specific diet concerns:
  - CF: protein, Calcium, vit D
  - GF: B vitamins
  - Hypoallergenic—use of alternative beverages
    - Goats milk—folate
    - Rice milk—protein, vits A, B12 and D, calcium
The vitamin takers
- Often megavitamins in response to family/peer pressure
- Often focus on nutrients/chemicals implicated in ‘changing the brain’
- Seldom consider child’s intake
- Risk of supplements interfering with actual food intake
- ‘oh I’ll just give him/her enzymes’—not at bedtime!!
- ‘oh I’ll just give him/her gummy vitamins’
  - No iron or calcium
  - ‘complete’ multivitamin
  - Acceptable to use infant MVI
Fostering the least restrictive feeding method
Feeding Methods

- Know the client’s swallow study results
  - No swallow study when ill
  - Laryngeal penetration does not mean aspiration
- Key terms in the report
  - Tiring with attempts
  - Aspiration
  - Texture tolerance
  - Recommendation for oral motor therapy
  - Recommendation for alternative feeding method
- When should a swallow study be repeated
  - Progress with skills
Feeding methods

- Provide nutrient adequacy in least restrictive form
- Consider oral feeding as tolerated, even if provides little nutrition
  - Social aspects of eating
  - Eating as pleasurable
  - Be adaptable!
Food based formulas

- Much parental interest due to
  - Anecdotal evidence that some children can wean off gtube feedings faster
  - Parental desire to move away from ‘chemicals’
  - Goal to move away from high sugar feedings, which may play a role in retching
  - Psychosocial benefit of being able to eat same foods as family (especially with home blenderized)
  - Lower cost if insurance does not cover cost of formula
GUT MICROBIOME: friend or foe

- What is the microbiome in ASD?
- Does the microbiome differ from that of neurotypical children?
- Does the microbiome differ in regions of the country?
- Does the microbiome explain differences between ASD +/- GI disorders?
Observations thus far

- Fecal concentrations of genera Prevotella and Coprococcus low; of Clostridia sp high
- Overall less diverse microbiome

- Is the gut-brain connection driven by microbiome metabolites??
- Stay tuned: brain-gut-microbiome axis research ongoing in multiple disease states
resources

- CF/GF/SF diet: tacanow.com—not a reputable source for autism information (taca = Talk About Curing Autism)
- General article on nutritional interventions: Geraghty ME. ICAN 2010, 2:120.
- General autism information, source for all: Autism Speaks
- Feeding difficulty (although not specific for neurocognitively delayed children): Feeding problems in children, in 23rd ed of Rudolph’s Pediatrics, 2018
How can I help my clients with suspected GI problems

Carol Redel MD MNS
Take home point:

- Any GI pathology found in a normally developing child can be seen in a child with neurocognitive delay.
- However, the symptoms of that GI disorder may bear no resemblance to those seen in neurotypical children.
Objective

- Participants will be able to state 2 atypical symptoms of constipation that may occur in a child with neurodevelopmental delay
GI Problems seen in ASD

- Reported 9-80% incidence of GI symptoms in children with ASD; most studies with sampling errors
- Increased incidence of
  - Constipation, stool withholding
  - (Diarrhea preventing potty training)
  - (GERD/EE)
  - Food selectivity
Constipation

- Has many contributors
  - No one likes cleaning up stool/some parents just aren’t aware of their child’s stooling habits
  - Some children don’t like stooling—role of anal sphincter
  - Lack of ambulation worsens
  - Low fiber diet
- Has many treatments, from food sources of fiber through prescription medications
Bristol Stool Chart
Constipation in ASD

- Is this related to neurosensory differences in the bowel?
- Suspected functional basis—parents aware of child’s need to stool but child withholds
- Red flags: bloody stools, weight loss
- Signs: distension, pressure on stomach, back arching, deterioration in sleep, food intake and attentiveness

Suggestions
- Sorbitol containing fruits (‘P’)
- Probiotics
- Fiber—in various forms
- Laxative use—PEG, lactulose
- Testing available—KUB, ARM
- ? botox
Educational Aid:

THE POO IN YOU: GI KIDS
Vomiting

- Differentiate among
  - Spitting or bringing up mucus
  - Gagging with immediate return of oral content
  - Emesis of food or formula—gastric contents; most commonly GER related BUT can be medication related

- Is there pain?
  - Ulcers, gastritis (+/- H pylori), pancreatitis
  - Underlying constipation/obstipation can mimic upper GI pathology

- Is there relief with vomiting?
  - Gastritis, eosinophilic disorders, gastroparesis

- Does it occur MANY times daily, but not when asleep
GERD in ASD

- Often associated with family history of gerd/dyspepsia
- Signs: gurgling in throat, spitting, vomiting, positional changes in head, abdominal discomfort, excessive drinking
- Areas of confusion: rumination, eosinophilic esophagitis, ulcer
- Suggested therapies:
  - Caffeine, hot pepper, tomato-based sauce avoidance
  - No food or drink within 2hrs of bedtime
  - Elevate head of bed (pillows or blocks)
  - Antacid trial
The special case of rumination

- Often listed in adult literature as psychiatric illness and/or eating disorder
- In children may be different—verdict is out
- Defined as repetitive regurgitation (+/- re-chewing) of already chewed and swallowed food, liquid
  - Can occur 10 to >100 times a day
  - No occurrences overnight
- Features
  - Effortless
  - No weight loss
Diagnosing Rumination

- Historically based on family’s recollection of occurrences
- pH probe: episodes of acidic pH in esophagus while awake only
- Standard of care currently: esophageal manometry with R waves
  - Requires testing while awake
  - Only done in centers with motility capability
Treating rumination

- If feeding orally
  - Chewing gum
  - Diaphragmatic breathing
  - Acid blockers
  - Treat underlying psychiatric diagnosis if present

- If feeding by tube
  - May be a hypersensitivity to a particular component of formula
  - Trial of acid blocker
Abdominal distension

- Is abdomen flat in the morning, with progressive increase in distension during the day? Consider aerophagia

- Is feeding better tolerated earlier in the day, tolerated poorly in the evening? Consider either gastroparesis or aerophagia

- Is the client a mouth breather?

- Did this happen acutely, or been gradual onset over months to years?
  - For acute, consider gastroparesis
  - For chronic, consider aerophagia
  - Consider giardiasis, celiac, H pylori
Aerophagia
Aerophagia remedies

- When possible teach child to keep mouth closed
- Treat allergies if present
- In gtube fed patient, consider trial of alternative formula
  - Protein hydrolysate
  - ? Intact formula
- Gastric air may be amenable to GasX/simethicone, but this only makes gastric bubbles smaller
- If gtube fed:
  - Decompress air before feeding
  - Positioning (rolling side to side)
  - Consider change to GJ tube, so gastric port can be used to decompress stomach
Diarrhea

- In many instances, pediatrician has sent infectious testing (bacteria, giardia, other O+P, viral)
- Unfortunately our clients can also develop IBD: Crohns disease and ulcerative colitis. The red flags: bloody stools, weight loss
- Does protein malabsorption always result in diarrhea?
- Consider malabsorption of either fat or carbohydrate
  - Both give more rapid transit through small intestine
  - Either can result in weight loss
Edema

- Consider protein adequacy, especially when client has reduced energy requirement
- Excessive losses can be due to protein losing enteropathy
  - Allergic in etiology
  - Risk following certain cardiac procedures, such as Fontan
  - Primary GI causes: intestinal malrotation and intestinal lymphangiectasia
Abdominal pain: teaching points

- 1. many of our clients with neurodevelopmental delay have high pain tolerance
- 2. if the client is additionally nonverbal, more testing rather than less, is typically necessary to elucidate the etiology
Volume tolerance issues

- Can have many causes: GER, delayed gastric emptying, aerophagia, behavioral

- Potential solutions:
  - Slow down feeding rate, or 6 small meals a day
  - Combination of small boluses and nocturnal drip
  - Continuous drip feedings
  - Use of high kcal dense formula
  - Trial of intact formula
Poor weight gain

- Is child being fed?
  - Many of our children do not indicate hunger
  - Feeding is a time commitment
  - Is food/formula available?
- Does child tolerate prescribed feedings?
  - Are feedings being stopped early due to abdominal distension or perceived discomfort
- Is the nutrition prescription accurate?
  - Moving from the wheelchair to:
    - Stander
    - Crawling
    - Walking, cycling