Nutrition and Autism

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Objectives

- Identify nutrition-related challenges frequently seen among children with ASDs
- Describe intervention approaches for nutrition-related issues
- Discuss the evidence behind some nutrition-/diet-related CAM approaches
- Share parent experiences
Common Behaviors in Children with Autism

- Difficulty with transitions
- Impaired communication skills
- Social interaction difficulties
- Easily overwhelmed or over-stimulated
- Short attention span
- Limited range of interests
- Need for routine
Behaviors in ASD Related to Possible Selective Food Patterns/Effects on Eating

1. Need for routine, difficulty with transitions

- Problems with changes in mealtime routines; tantrums can result
- Refusal of an unfamiliar food, dish, or location
- Limited number of accepted foods/decreased acceptance over time
- Late acceptance of solids as an infant
Behaviors in ASD... Effects on Eating

2. ↑ sensitivity to texture, taste, temperature, & smell; easily overwhelmed or over stimulated

- Restricted intake due to hypersensitivity
- Restricted intake due to refusal of specific color, texture, temperature, odor
- Difficulty in making transitions to new textures or tastes
- Refusal of vitamin/mineral supplements that may be needed
- Possible gagging, vomiting
Behaviors in ASD Related to Possible Selective Food Patterns/Effects on Eating

3. *Short Attention Span*
   Loses interest in eating after only a few minutes

4. *Impaired Social Interaction and Communication Skills*
   Less responsive to positive eating behaviors modeled by others
What do families say? (survey of families with ASD)

- Does your child have problems with eating?  
  Yes: 77% (refusal of new foods, limited selection, disruptive behavior at mealtime)

- Do you feel your child eats enough?  
  Yes: 47%

- Does your child have strong dislikes?  
  Yes: 93% (Dislikes: texture, color, temperature, flavor, food combinations)

- Does your child eat what the rest of the family eats?  
  No: 38% (More than 2/3 of families make separate/special meals for their children)
What does the typical intake look like for a child with autism?
ASD – Nutrition Status

- **Growth:** tends to be typical and within normal limits
- **Intake:**
  - Energy and protein needs usually met
  - Vitamins/minerals at risk if very “picky eating” or eliminating entire food group
  - Risk of excessive vitamin/mineral intake, with some supplements
  - Elimination diets can result in several nutrients being marginal or deficient
- **Physiologic needs are the same (energy, vitamins, minerals)**
- **Often, primary concern is “picky eating” aka “food selectivity”**
Other (less common) nutrition-related challenges

- Pica
- Compulsive eating
- Mouth packing
- Emesis, gagging, rumination
- GI problems (e.g., constipation, diarrhea, reflux, vomiting); referral to specialist, if problem is suspected
Incidence Study of GI symptoms


- **Study range 1976-1997; n = 124 with diagnosed autism and 2 matched controls per subject**
- **Followed to ~ 18 years of age**
- **Significant findings:**
  - Constipation (33.9 vs 17.6%)
  - Feeding issues/food selectivity (24.5 vs 16%)
- **No sig. diff. in overall incidence of GI symptoms in other GI categories**
- **2010 Consensus/Recommendations (Peds) for eval/diagnosis/treatment of GI issues**

Pediatrics 2010;125:S1-S18 and S19-S29
Constipation

*Possible non-verbal symptoms*

- Child not sleeping well
- Abdominal discomfort, holding or pressing on abdomen
- Crying
- Less intake than usual
- Tantrums
Strategies to improve eating: the dilemma

- Children with ASDs have persistent food preferences and feeding behaviors
- Standard anticipatory guidance from health professionals (if he is hungry, he will eat) has not worked
- Families have “tried everything”
Strategies to improve eating: solutions

- Requests to eat vs. pleading/threatening
- Child can leave the table when the family is finished
- Modeling behaviors:
  - Eating fruits and vegetables
- “Families are likely to need support in establishing mealtime structure.”

Strategies to improve eating: solutions

- Routine meals and routine snacks
  - No food or drink between scheduled meals/snacks
- Calm mealtimes, minimize distractions
- Family meals
- Self-feed, if able
- Menu: foods that the family eats, including at least one food that the child is known to accept
Strategies

- Avoid overwhelming the child – limit changes
  - Keep mealtimes constant – plates, utensils, place, time
  - Small servings of 2-3 foods at a time... avoid too much food and too many choices
  - Offer new foods along with foods the child already likes to eat

- Introduce foods in forms similar to accepted foods; make gradual changes:
  - Sandwiches made with crackers
  - Sandwiches made on toast
  - Sandwiches made with bread

Adapted from *Nutrition Focus (Lucas et al, 2000)*
Strategies to improve eating: solutions

- Feeding evaluation at diagnosis for early feeding interventions if needed (team approach)
- Individualized help from ITEIP, school, & therapists with appropriate educational interventions (ABA strategies)
- Identify family values/expectations
- Determine child’s unique learning style & developmental level
- Start with single focus, food, or task
- Persistence and consistency – can take weeks or months
The Step-Wise Approach

- **Choosing the food**
  - similar to those child likes
  - different brands of same food
  - change shape or appearance slightly
  - add new food to preferred food

- **When and where**
  - may not be mealtime
  - child should be hungry but not starving
  - not rushed

- **Structure**
  - same location, time, feeder, time

- **Rules**
  - where child can spit out

- **Works well in feeding groups**
Eating (and enjoying food) is not as simple as it looks. Eating is an interactive process with many steps:

1. **Eats food**
   - 1. chews and swallows independently

2. **Tastes food**
   - 1. licks food
   - 2. bites food

3. **Touches food**
   - 1. with fingers, hands
   - 2. with mouth

4. **Smells food**
   - 1. in room
   - 2. at table, on plate

5. **Tolerates food**
   - 1. in room
   - 2. at table
   - 3. on plate

Adapted from “Steps to Eating” Kay Toomey, PhD., Denver, CO
Strategies – continued

- Expect *slow* changes. Follow the child through the steps of the process... set realistic goals.
  - Child will let peas stay on plate
  - Child will pick up peas, but not put in mouth
  - Child will lick peas
  - Child will take a bite of peas

- Encourage families to ask others for help.
  - Offer same “goal food” at snack time and/or lunch and at home
  - Consider non-food reinforcers
  - Incorporate eating into existing reward systems, for example:
    - Rewards for leaving peas on plate (not on floor)
    - Staying at the table
  - *Rewards – food Y/N?*

Adapted from *Nutrition Focus (Feucht/Ogata 2010)*
Mealtime Stories

- Personalized books for children with persistent feeding difficulties
- Books that affirm the child’s accomplishments/illustrate current goals
- Approach considers education, behavior, therapy, and mental health issues
- Idea is to help children with feeding issues and their families and a therapy tool
Mealtime Stories

- An actual mealtime story book was shown but presenter only has permission to use in presentation and not on a website. If you want more information on constructing a mealtime story book you can visit this website:
  - http://www.mealtimestories.com/
Nutrition Interventions in School

- Interventions can be incorporated into a child’s educational goals – in the written IFSP (Individual Family Service Plan) or IEP (Individualized Education Plan).
- Requires cooperation of the school and the family.
- Provides consistent behavioral approach for both education and feeding goals.
- RD role as contributor to educational team.
Child Nutrition Programs - School Meals

- All children in public schools are eligible for school meals.
- Children with special needs can receive modified meals, depending on disability (Section 504 of federal law).
- Documented diet prescription is required.
- Examples: high calorie, low calorie, diabetic, soft, documented food allergy.
Nutrition/Feeding Goals in IFSP/IEP

For instance:

- Progress in oral motor or self-feeding skills
- Supporting improved growth, weight gain, or weight loss
- Modified school lunch and/or breakfast
- Management of eating/mealtime behaviors, i.e. encouraging more food variety in children with ASD
Complementary and Alternative Medicine (CAM)

- **Definition** - CAM is a group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine (also known as Western or allopathic medicine)

Types of CAM

- Mind-body medicine - yoga, acupuncture, prayer, Tai Chi, dance, music, meditation

- **Natural Products** - Vitamins, minerals, probiotics, foods, other dietary supplements

- Manipulative and body-based practices – manipulation of body/massage

- Other – movement therapies, energy fields, whole medical systems (Ayurvedic/Chinese medicine)

*National Center for Complementary and Alternative Medicine – accessed 4/15/2011*
The Family View (CAM)

- ASD diagnosis with unknown etiology, unsure of effect of other treatments
- Education/behavioral interventions take time, energy, resources – slow progress
- Concern for health, diet (the extreme picky eater)
- Promotion of alternative therapies from other families, internet, listserves
- Families have choices & control in a situation where they may feel helpless
Considerations

- Is the product safe?
  - What is in it?
  - What pediatric studies have been completed?
  - Does this react/interfere with other meds?
  - What is a safe dose for a child?

- What is the cost to the family?
  - Does it interfere with funds for basics (food, housing, prescription meds)?

Adapted from Elder, 2008
Considerations – continued

- Does it work?
  - Have there been efficacy studies/outcome measurements in children?
- Will it augment or replace conventional therapy?
- How will it be evaluated?
  - What will be monitored?
  - Which change related to which therapy?

Adapted from Elder, 2008
Considerations – continued

- What are the possible harmful effects?
  - Nutrients?
  - Food pattern?
  - Expense?
  - Other resources?

Adapted from Elder, 2008
Evaluate “Research”

How large was the sample size?

Were the researchers “blinded” to the intervention?

Was the study a RCT? (randomized control trial)

Were objective tools used to measure study outcomes?
Complementary & Alternative Therapies

Diet Restrictions
- Gluten-free, casein-free diet
- Specific carbohydrate diet
- Food additives
- Yeast-free diet
- MRT Testing/LEAP

Supplements
- Vitamin B6 and magnesium
- Omega-3 fatty acids
- DMG/TMG
- Others: Co-Q10, zinc, vitamins A/C/E

Combination
- DAN Protocol – Now Autism Research Institute – diet, supplements, other
Theory of “Leaky Gut”

- ↑↑ intestinal wall permeability allows partially intact protein (peptides) into bloodstream
- Substances cross blood-brain barrier
- Opioid-like molecules from the incomplete breakdown of protein affect the central nervous system and cause disruption in neurotransmission
- Therefore, GFCF diet
GFCF Diets for ASD: Anecdotal Data vs. Research

- Anecdotal reports of improved behaviors/symptoms
  - eye contact, sociability, language
  - bowel movements, sleep patterns

- Research limitations:
  - Few double-blind, placebo-controlled studies
  - Dietary intake not clarified/measured
  - Small sample sizes
GFCF Diets – The Evidence

- Cochrane Review (2008) – 2 studies
  - N<20 for each
  - Knivsberg, 2002 - significant improvement autistic traits but wide confidence intervals
  - Elder et al, 2006 – no differences noted on CARS, ECOS, behavior assessment, or urinary peptides; showed good feasibility and compliance

- Whiteley, 2010
  - 2 stage, single blind 24 month trial – other non-nutrition interventions continued
  - N=72 at start in 2 groups - Diet A for 24 months, Diet B for last 12 months
  - Results – Significant differences in autistic/related behaviors at 8/12/24 months - less dramatic changes between 8-24 months
Considerations re: GFCF Diet

- Possible compromised nutritional intake
  - Protein
  - Calcium
  - Vit. D
  - Zinc
  - B vitamins
  - Folate

- Substitute products do not always provide the same nutrients, including fiber
- More products available with ↑ celiac disease
GFCF Diets – The Evidence

- Research still considered to be inconclusive at this time
- Some children may benefit from GFCF but all must remain objective: consider expectations for success
- GFCF diet considerations – DIET is not a cure for ASD
  - at risk for inadequate nutrient intake
  - will child eat this diet?
  - expense/energy to buy/prepare food; impact on family budget for other purchases
  - difficulty sticking to diet ⇒ “failure”; stress/pressure on child; everyone involved “on board”
  - social separation for family
- Need to have nutrition services to ensure nutrient needs and intake are appropriate for growth and development
Typical intake for a child with autism
...without gluten
Other CAM for ASD

- No RCT to support effect of B6 & Mg (Nye & Brice, Cochrane Coll Rev, 2002)
- Omega 3 fatty acid supplements – no good studies for ASD but popular; food sources – flaxseed, canola, soybean oils; fatty fish, fish oils; fortified foods
- Other CAM listed not supported with research; ? of safety; need nutrition assessment
Dietary Reference Intakes - Tolerable Upper Limits (UL)

- Magnesium – from supplements only
  - 65 mg (1-3 yr)
  - 110 mg (4-8 yr)
  - 350 mg (9+ yrs)

- Vit B6 – 30, 40, 60 mg/day
  (CAM often used is Super Nu-Thera: 75 mg magnesium; 225 mg Vit. B6. B6 exceeds UL noted above for all children and Magnesium is above UL for 1-3 yr)

No RCT to support effect of B6 & Mg (Nye &
Aaron

- 3 years old with Down syndrome & Autism
- ? Celiac disease? – (+) blood tests; (-) biopsy
- History of FTT, poor growth, picky, neophobic
- No dairy (nasal congestion); Intermittent GF diet
- Chronic constipation
- Eats regular meals/snacks with family
- Requires food be presented in routine manner
- Uses a bottle (rice milk)
- Borderline iron deficiency anemia
Case Examples

- Note – we did not cover these case examples due to timing. However, the presenter included them here for your information.
Aaron - Assessment - supplements

- NuTriVene-D powder
- Probiotics
- IgG Pure whey protein powder
- Biogenesis Intestinal Repair Complex
- Flax seed meal
- Cod liver oil
- Piracetam
- DHA
- zinc
Aaron – nutrition assessment

- Diet intake – low in vits A, C, E; iron, EFA (thus supplements are needed)
- Vit A - ~1500 μg from suppl
  (Upper Limits-UL = 600 μg)
- Zinc - 40 mg from suppl (UL = 7 mg)
- Piracetam, IgG Pure and probiotics – no evidence, but safe
Aaron - Nutrition Diagnosis (PES)

- Inadequate oral food/beverage intake related to diet selectivity and elimination as evidenced by parental report, food record and Fe lab values.

- Excessive intakes of supplementary vitamin A and zinc related to multiple nutrient sources as evidenced by 2.5 times the vit A UL and >5 times the zinc UL for age.
Aaron – Nutrition Intervention

- Modify supplement intake to RDA & <UL; eliminate cod liver oil and zinc
- Education to ↑ calcium-fortified rice milk & other calcium food sources & iron sources
- Consider replacing Nutrivene-D with complete pediatric multiple vit-mineral
- Continue with GF diet; follow up with PCP
Mary

- 4 years old
- Development appeared appropriate until 18 months of age; regressed in speech, social skills, and communication
- Autism diagnosis
- Decreased variety in food intake; picky
- Gets upset at meal times
- Encopresis – managed at specialty clinic
Mary - Assessment

- Slowed weight gain; same height %’s
- Stopped drinking milk at 2.5 years of age; drinks dilute apple juice
- Prefers crunchy foods (cereal, fish crackers, pretzels)
- Will eat bagels, crackers, pepperoni pizza, grilled cheese or quesadilla, chicken nuggets
- Apple 5/7 days; strawberries 2/7 days
Mary – Assesment – medictions

- MiraLax
- Mineral oil (mixed into raspberry juice and made into popsicles – eats 2 daily
- Costco L’il Critters (4 days per week) – no iron or calcium
- Fluoride
Mary – Nutrition Diagnosis

- Low energy, vitamin and mineral intake secondary to food texture preferences as evidenced by a decreased rate of weight gain
- Encopresis/constipation secondary to low fiber intake evidenced by need for MiraLax and mineral oil
Mary – Nutrition Interventions

- To increase Mary’s food variety consider a program with a feeding therapist using the food chaining, Sequential, Oral, Sensory (SOS) Approach to Feeding, or an adapted applied behavioral approach.

- To meet calcium and Vitamin D needs – Use an apple juice with calcium and Vit D with less dilution; offer vitamin everyday; try to offer 1.5 ounces of cheese daily; read cereal labels to select ones with calcium.
Mary – interventions cont’d

- Offer foods with 3-5 grams of fiber/serving
- Monitor growth; weight gain with PCP
- Provided name of local nutritionist if family wanted follow-up
Lyle

- 27-month old
- Recently diagnosed with autism
- Receives educational and speech services through local early intervention center
- No concerns re: growth
- Supplements: CoQ10, vitamin C, DHA, Super NuThera, folic acid, DMG, zinc, melatonin spray

Feeding history
- Early: unremarkable
- 16-19 months: began refusing previously accepted foods, and stopped trying new foods
- 27 months: refuses to try new foods, sometimes gags when a new or non-preferred food is offered
Lyle – continued

- **Assessment/Concerns**
  - Estimated intake is adequate (based on growth, food record), except for iron
  - Intake from supplements seems safe
  - Concur with family’s concerns about selective food pattern
Lyle – continued

Strategies they’ve tried

- “Sneaking in” new foods – he picks out the hidden food
- Eating together as a family
- Scheduled/structured meals and snacks (about every 3 hours); no food/drink in between

Recommendations

- Continue to make mealtime enjoyable
- “Steps to Eating”
- Expectations, based on other behaviors
- Pairing new foods with accepted foods
- Regular meals and snacks
- Supplement with iron
Lyle – follow-up

- Feeding therapy added
  - Sensory-based approach
  - Pairing new foods with preferred foods → pizza!

- Planning discussion about gluten-free/casein-free diet
  - Gluten +/- casein
  - Monitoring for effectiveness
  - Transition to gluten-free PBJ, pizza crust
Resources

- Nutrition Focus Newsletter – Nutrition concerns of children with ASD, includes resources at the end – The issue related to autism was provided as a handout at the conference.
Resources

Website – Nutrition – children with special health care needs Washington State Gateway to many resources including WA State Community Feeding Teams; Nutrition Interventions for CSHCN and more

http://depts.washington.edu/cshcnnut/
Resources

- Washington State Medical Home website – provides information on a variety of diagnosis plus a wide array of information for families, physicians, and others.
- http://www.medicalhome.org/
Resources- Feeding Therapy

- **Just Take a Bite: Easy, Effective Answers to Food Aversions and Eating Challenges!** (Paperback)
  *By Lori Ernsperger, Ph.D & Tania Stegen-Hanson, OTR/L*

- **Mealtime Stories** (Guidebook and CD)  *By Maggie Tai Tucker, MOT & Mary Neifert, MOTA*
  Mealtime Story is a personalized book-making and book-sharing intervention for children of any age. The Mealtime Stories Kit includes a detailed Guidebook and CD of templates and photos to carefully direct you through the 10 step process. www.theraproducts.com

- **Food Chaining: The Proven 6-Step Plan to Stop Picky Eating, Solve Feeding Problems, and Expand Your Child’s Diet.** (Paperback)
  *By Cheri Fraker, Mark Fishbein, Sibyl Cox and Laura Walbert.*  2007