Can Children with Autism Eat and Be Nourished?
What’s New, What Helps?

May 4, 2017
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Objectives

• Review recent evidenced based research regarding nutrition, feeding and behavioral issues in children with Autism Spectrum Disorder.
• Understand key concepts of feeding development and relationship based intervention.
• Identify parent feeding practices, eating patterns and foods that support or disrupt feeding development and regulation of hunger and satiety.

Common Behaviors in Children with Autism Can Impact Eating

• Sensory impairments (feel, smell, sound)
• Social skill and/or communication deficits
• Rigid behaviors, difficulty with minor changes and/or transitions (need for routine, same foods)
• Easily overwhelmed or over-stimulated
• Unusual interests and behaviors (focus on details)
• Short attention span

Autism Treatment Network - Nutrient Intake Study

• Overall both groups consumed similar amounts of nutrients
• Few children in either group met fiber, choline, calcium, Vits D, K and potassium
• All exceeded RDA- protein
• No group met DRI-fiber
• ASD - 66% used supplements
• ASD - 4-8 y/o - less energy (greater % from CHO), Vits A, C, Zn
• Excess intakes – Varied with age for sodium, folate, manganese, ZN, Vit A, selenium, copper (but ASD less likely NA, more likely ZN, A, folic acid)
Autism Treatment Network - Nutrient Intake Study

• Weight
  • 2-5 y/o with ASD more likely to be overweight/obese
  • 5-11 y/o with ADS more likely to be underwt
  • No difference in # of nutrient deficits across various weight categories for those with ASD
  • 18% of those with ASD on restricted diets; no difference in nutrient deficits; more likely underweight

Feeding Problems and Nutrient Intake in Children with ASD

• 2013 Meta-analysis – 17 studies met criteria
  • Children with ASD had significantly more feeding problems
  • (Fivefold increase)
  • Lower intake of calcium and protein; other nutrients
  • In spite of the feeding difficulties and nutrition concerns growth is not at greater risk; may mask nutrient concerns
  • Why nutrient intake? Suspect food selectivity and/or elimination diets


Recommendations from Meta-analysis

• Include assessment of feeding problems at routine medical checks
• Screen for nutrient deficits/excesses & growth
• Educate caregivers that evidence for diet modifications in ASD is tenuous
• Review consequences of elimination diets based on child’s unique feeding and nutrient information

ASD and GI symptoms


• 1980-2012; 15 studies (2215 children with ASD)
• Significance – Children with ASD compared to others experience elevated risk:
  • 3x general GI symptoms, constipation, diarrhea
  • 2x abdominal pain
No significant difference noted in other GI categories

Behaviors That May Indicate Abdominal Pain/Discomfort in Children with ASD (Buie, 2010)

<table>
<thead>
<tr>
<th>Vocal Behaviors</th>
<th>Motor Behaviors</th>
<th>Changes in State</th>
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<tbody>
<tr>
<td>Frequent throat clearing</td>
<td>Facial grimacing</td>
<td>Sleep disturbances</td>
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<tr>
<td>Screaming</td>
<td>Gritting teeth</td>
<td>Increased irritability</td>
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<td>Sobbing for no reason</td>
<td>Wincing</td>
<td>Noncompliance with demands that typically elicit an appropriate response</td>
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<td>Sighing, whining</td>
<td>Mouthing behavior</td>
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<td>Moaning, groaning</td>
<td>Tapping behavior</td>
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<td>Delayed echolalia</td>
<td>Any unusual posturing</td>
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<td>Direct verbalization</td>
<td>Agitation</td>
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<td>Self-injurious behavior</td>
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<td>Aggression</td>
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Bill of Rights for ASD

“Individual with ASD deserves the same thoroughness and standard of care in the diagnostic workup and treatment of GI concerns as should occur for patients without ASD”

Behavioral treatment should not substitute for medical intervention

Educate parents/PCP

• Screen for possible GI
• Consider lower threshold for evaluation in ASD
• Consider child's ability to communicate and review behaviors
• Need evidenced based guidelines; variety of treatments

New Tool – Nutrition Management of GI Symptoms


Research Studies in Process

• Profile intestinal bacterial of children with GI concerns; found bacteria in those with ASD not seen in children without ASD
• Evaluate if a probiotic can relieve anxiety/ improve quality of life in children with ASD
• Treat those with ASD and chronic constipation with highest standard of care; assess behavior/analyze blood for signs of oxidative stress
Family/Professional Resources
https://www.autismspeaks.org/tn/tool-kits

Exploring Feeding Behavior in Autism - A Parent’s Guide

Integrative Medicine in ASD

• 28% - any use
• 17% - special diets
• 20% - other

• Higher use associated with
  • GI symptoms
  • Seizures
  • CBCL total problem score
• No association with sleep problems
• Lower use of special diets with use of psychotropic meds


Dietary Supplementation –

288 children with ASD (age 2-11 years)
3 day diet/supplement records (some on GFCF diet)
56% used supplements (multivitamin/minerals most prevalent, then single nutrients)

Most common deficits not corrected with supplements – Vit D, calcium, potassium, pantothenic acid and choline
Excess intake of Vit A, folate, and zinc in all

Integrative Medicine in ASD

Diet Restrictions
• Gluten-free, casein-free diet (GFCF)
• Specific carbohydrate diet
• Food additives
• Yeast-free diet
• Mediator release test (MRT) – non IgE
• Lifestyle Eating and Performance (LEAP)

Supplements
• Vitamin B6 and magnesium
• Omega-3 fatty acids
• Dimethylglycine supplement (DMG), Trimethylglycine (TMG)
• Others: Co-Q10, zinc, vitamins A/C/E

Combination
• DAN Protocol – Now Autism Research Institute – diet, supplements, other

288 children with ASD (age 2-11 years)
Review of Systematic Studies

<table>
<thead>
<tr>
<th>Type of Studies</th>
<th>Articles Included</th>
<th>Study Population #</th>
<th>Conclusions</th>
<th>Future</th>
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<tbody>
<tr>
<td>Randomized Controlled Trials (RCTs)</td>
<td>2009/2010</td>
<td>2009 - varied between 2 to 10 subjects</td>
<td>N = 15</td>
<td>No statistically significant findings - GiS, urinary peptides, in-home observation</td>
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<td>Elder 2006</td>
<td>RCT double-blind</td>
<td>15 followed 12 months</td>
<td>No statistically significant findings - CARS, urinary peptides, in-home observation</td>
<td>Future study needed</td>
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<td>Single study to parents knew group</td>
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<td>72 at start; dropped to 20/37 controls; final 38/17</td>
<td>Reduced artistic traits</td>
<td>Need more studies; parents knew group</td>
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<td>Hyman 2016</td>
<td>Double blind challenge trial</td>
<td>54</td>
<td>Start - 46 weeks of GFCD next 12 weeks - One day/week challenge with provided snack containing gluten only, casein only, gluten and casein, or neither with behaviors observed by research assistant, parent, and RBA therapist (5 days) next 12 weeks - Children remained in study and families chose to maintain, stop, or modify diet</td>
<td>Small numbers but study does not provide evidence to support general use of GFCD diet</td>
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One Group’s Recommendations

- Physical signs and symptoms
  - FTT, GI, Skin...
  - Same as for general pop’n
- Parent education
  - Inconclusive evidence
  - Practical considerations
  - Difficult to r/o effects of other interventions
- Medical safety
  - r/o celiac disease, FTT
  - Consider gradual introduction if intake is already limited
  - RDN guidance
  - Monitor growth
- Measuring treatment response
  - Systematic observations
  - Behavior goals
  - Trial duration 7 - 12 wk/stage


Randomized Controlled Trials (RCTs)

<table>
<thead>
<tr>
<th>Study</th>
<th>Type</th>
<th>Number</th>
<th>Study design &amp; duration</th>
<th>Findings &amp; Comments</th>
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<td>72 at start; dropped to 20/37 controls; final 38/17</td>
<td>GFCD diet may positively affect developmental outcome but could not rule out intervention outside of dietary</td>
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Reference – Complementary and alternative medical treatments


- Provides extensive table with grading of the evidence (number of studies and type) that indicate support to use or not & comments
Feeding Development

- Inborn drive to satisfy physical states (sleep, elimination, hunger/satiety)
- Response weakens with growing internal and external needs and distractions
- Hunger isn’t always the priority
- Interactions support or disrupt

Helping Children with Autism Eat and be Nourished

Nutrition Considerations

Learned behavior and dysregulated physical states sustain feeding problems over time

Avoidant Restrictive Behaviors

Developmental
Oral motor
Sensory processing
Repetitive rigid routines
Language Delays

Environmental Psychological
Anxiety
Parenting
Patterns of reinforcement
Punishment

Texture, Flavor, Smell, Color, Brand, Temperature, Presentation, Rigid Routines

Medical/Physiological
Constipation
Superstitious
Vomiting

J Am Diet Assoc 2006;106 (1 supp 1):S77-S83
Laam Motiv 1987;18:301-317
Primary parent goals:
- increase food variety
- adequate intake for growth
- enjoy food, eat with family

Effective Intervention & Support
Requires Careful Consideration

- Contributing factors
- Learned behaviors
- Functional analysis
- Patterns of reinforcement
- Effective reinforcement for positive behavior

Building a Strong Foundation
Optimizing Hunger and Satiety

- Interest in eating
- Focus on eating
- Engaged in feeding session
- Consistent intake (balance and quantity)
- Flexibility
- Interest in new foods
- GI function
- G-tube feedings

Focus on Preferred Foods

<table>
<thead>
<tr>
<th>Preferred Foods</th>
<th>Moderately Preferred Foods</th>
<th>Novel Foods</th>
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FIGURE 2.7 SATISFACTION FROM CONSUMING SUGAR, STARCH, PROTEIN, AND FAT

Sugar | Starch | Protein | Fat

Hunger

Meal or Snack | Time
**Calen**

7 year old

*Diagnoses:*
- Feeding difficulties
- Autism Spectrum Disorder
- Language Delays
- Disruptive Sleep
- Constipation

*Referred by:*
- Neurodevelopment Clinic Medical Provider
- Occupational Therapist

*For:*
- Liquid dependence
- Restricted intake of textured solids

*Team Assessment January 2017*

*Parent Goals:*
- Increase acceptance of food/variety

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**Education - Motivational Interviewing**

- Eating patterns, hunger and satiety
- Food selection
- Target foods, behaviors
- Parenting skills, vocabulary
- Reading and responding to hunger
- Highly collaborative intervention process!!

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**Milk = 16-24 oz per day**

Juice < 4oz per day

- **Protein/Fat**
  - Milk Yogurt Cheese
  - Chicken nuggets

- **Starch**
  - Potatoes Carrots

- **Fiber**
  - Bananas Oranges

- **Condiments**
  - Cream dressin, butter dressings

**Education**

- Motivational Interviewing
  - Eating patterns, hunger and satiety
  - Food selection
  - Target foods, behaviors
  - Parenting skills, vocabulary
  - Reading and responding to hunger
  - Highly collaborative intervention process!!

**1-2 years**
- Milk dependent, dry crunchies

**2-3 years**
- Early Age Developmental Center Neurology, Neurodevelopment, Autism Center
- PCP – chronic constipation
- Speech therapist (delay in receptive language)

**5 years**
- OT - focus on regular meals and snacks
- RD - started Pediasure
- PCP – chronic constipation
- Parents pushing water, fruits, veggies

**5-7 years**
- Screams, gags, vomits w/presentation of new foods
- Refuses oral intake at school
- Napped grazed after school
- Disrupted sleep
- Chronic constipation

**7 years**
- Intermittent total oral refusal

**Oct 2016**
- Severe constipation, vomiting
- Decreased intake and wt loss
- PCP – started Pediasure w/fiber
Interdisciplinary Assessment

**Growth**

- BMI ~ 50-75th% (4-7 yrs)
- Acute wt loss (Oct 2016)
- Baseline BMI resumed (Jan 2017)

**Daily Intake**

- 7:00AM (home, in bed) 8 oz Pediasure
- 7:30AM (home in bed) 8 oz Pediasure
- 11:30AM (school) 8oz Chocolate milk, chips
- 2:15PM (school) Sips of water, crackers
- 4PM to mid-night Grazes
- Mid-night to 7AM Wakes 2-3 x for milk

**Target Intake**

- Fluid kcals: % needs
- Solid kcals: Variable
- Intake low in multiple nutrients
- Fluid volume meets maintenance needs (low in water)
- Irregular eating pattern

**Target Behaviors**

- Screams, gags, vomits presented w/ non-preferred
- Grazes, won’t sit for meals
- Rigid routines (cup, brand specific)
- Sensitive to touch (washes hands)

Interdisciplinary Assessment

- Oral- motor and swallowing skills - functional
- Language - improving
- Sleep – disrupted

- Stooling – mix of hard and soft 1-2x per day
- No recent labs

Interdisciplinary Treatment

- Stabilize nutrition and growth
- Eating patterns
- Preferred fluids/solids
- Daily fluid goals
- Supplements
- Lab request
- Referrals
Follow up visit #2

- S/p illness vomiting, total oral refusal
- Lab (ferritin low)
- Iron supplement recommended
- Liquid stools
- Parent decreased milk and Pediasure
- Weight gain

Intensive Day Treatment

Target Symptoms:
- Significant food refusal when asked to try novel or non-preferred foods
- Significant restrictive intake (i.e., consumes only limited brand specific dried crunchy foods orally he refuses all fruits, vegetables, starches and proteins)
- 100% liquid dependence upon Pediasure with fiber for caloric and fluid needs
- Refusal to drink anything by mouth other than Capri Sun
Intensive Day Treatment

Target Nutrition Goals:
- Fluid intake = 20-40%
- Solid intake = 70-80% estimated needs

Target Foods/Fluids:
- Water, 4oz juice
- Balanced solids (protein, starch, fruit/veggie)
- Fiber containing solids

### Week 1

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<th>Time</th>
<th>Solid</th>
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### Week 2

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May 4, 2017
Out-Come - Acceptance of Solids

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<tr>
<th># of BITES</th>
<th>% ACC</th>
<th>% TOT. REF.</th>
<th>% CI</th>
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Novel Foods:

Important Points

- Avoid change that reinforces avoidant behaviors
- Stabilize nutrition/growth, sleep and elimination
- Identify target goals
- Be systematic, ask questions, take data, one change at a time
- Advocate for evidence based intervention
  - AutismPFP@seattlechildrens.org

References