Increasing Awareness of Potential Nutritional Calamities in Children with Autism

RDs in Practice: Specialized Diets and Nutritional Management of Gastrointestinal Issues
Children’s Hospital Orange County
5.13.15

Carol Henderson, PhD, RD
Medical Advisor, Autism Nutricia North America, Rockville, MD
Objectives:

1. Understand diagnostic criteria for ASD and its prevalence.

2. Recognize the unusual manifestations of GI issues in hypo- or non-verbal children with autism and how they may be identified.

3. Recognize primary contributors to nutritional deficits in children with ASD including: Feeding problems, GI issues and food allergies.

4. Describe commonly occurring nutritional deficits that have been reported in children with ASD.
Background: Autism diagnosis by DSM V

Must meet criteria A, B, C, and D: (ASD term eliminated)

A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays

B. Restricted, repetitive patterns of behavior, interests, or activities

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)

D. Symptoms together limit and impair everyday functioning

What is the U.S. prevalence of autism in 2014?

- 1 in 42 boys have ASD
- 1 in 189 girls have ASD
- ASD is ~5 times more common among boys than girls

Who is affected?

-Occurs in all racial, ethnic and SES groups
-Symptoms are often evident by age 2
-Median age for diagnosis = 4 years 5 months
-Diagnosis can be made as early as 18 months

Autism is Heterogeneous

Co-morbidity in Autism commonly discussed:

1. Genetic syndromes
2. Associated psychopathology
3. Medical conditions:
   - Epilepsy
   - GI Disorders
   - Food Allergy
   - Immune Dysregulation
   - Catatonia
What are known causes/risk factors for Autism?

- Scientists aren't certain about what *causes* autism.
- Likely many causes for the multiple types of autism.

<table>
<thead>
<tr>
<th>Environmental, biologic and genetic risk factors:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Genes</td>
</tr>
<tr>
<td>2. Genetic or chromosomal conditions: Fragile X syndrome, tuberous sclerosis</td>
</tr>
<tr>
<td>3. Drugs during pregnancy: valproic acid and thalidomide</td>
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<tr>
<td>4. Greater risk of ASD if sib has been diagnosed with ASD</td>
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<tr>
<td>5. Children born to older parents</td>
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<tr>
<td>6. Critical age for developing ASD occurs before, during, and immediately after birth</td>
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</table>

Can autism be managed?

- There is no cure for autism
- Therapies and behavioral interventions exist
  - Remedy symptoms
    - Can bring about substantial improvement
- Ideal treatment plan is coordinated and individualized
  - Educational therapies
  - Medications
  - Other management options: Nutrition
- The earlier the intervention, the better

Each child’s symptom profile is unique
Medication Use in ASD

- In U.S. 33,565 children with autism, 64% had prescription for 1 psychotropic medication, 35% had psychotropic polypharmacy
  - Stimulants
  - Antipsychotics
  - Mood stabilizers
  - Antidepressants
  - Antianxiety agents


Mandell et al. *Pediatrics*. 2008;121(3)

- Medication use is highest among older children

- Other drugs used can contribute to excessive weight gain (SSRI) or insufficient weight gain (stimulants)

Coury et al. *Pediatrics* 2012;130:S69–S76.

## Medication Use in ASD

<table>
<thead>
<tr>
<th>Health Risk</th>
<th>Nutritional Risk</th>
<th>Associated Medications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Osteoporosis/Bone Fracture</td>
<td>Altered metabolism of Vitamins $B_{12}$, $B_6$, $D$, $K$, Calcium, magnesium</td>
<td>Anticonvulsants</td>
</tr>
<tr>
<td>Bone demineralization</td>
<td>Decreased absorption of calcium and magnesium</td>
<td>Proton Pump Inhibitors (PPI)</td>
</tr>
<tr>
<td>Impaired eating / swallowing</td>
<td>Altered facial and tongue musculature</td>
<td>Anti-psychotics (Risperadone, Chlorpromazine, Olanzapine, Quetiapine, Lithium)</td>
</tr>
<tr>
<td></td>
<td>Xerostomia</td>
<td>Serotonin Selective Reuptake Inhibitors</td>
</tr>
<tr>
<td></td>
<td>Depressed oral awareness and voluntary muscle control</td>
<td>Anticonvulsants (Clonazepam, Phenobarbital, Gabapentin, Valproic Acid)</td>
</tr>
<tr>
<td></td>
<td>Gum hypertrophy</td>
<td>Anticonvulsants (Phenytoin)</td>
</tr>
<tr>
<td>Obesity, metabolic disorder</td>
<td>Insulin resistance, excessive weight</td>
<td>Antipsychotics (Risperadone)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Anticonvulsants (Gabapentine)</td>
</tr>
<tr>
<td>Reduced appetite</td>
<td>Poor weight gain, insufficient caloric or nutrient intake</td>
<td>Anticonvulsants (Topiramax)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Stimulants (Methylphenidate, Atomexidine, Amphetamines)</td>
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</tbody>
</table>
“Individuals with ASD have the same medical disorders/diseases that affect neurotypical persons, although they may present differently.”

Many “autistic behaviors,” such as aggression and self-injurious activity, have been attributed to be just “part of the autism.” As a result, the patient with ASD is frequently referred for behavioral management and/or psychopharmacological intervention because of failure to interpret these behaviors as indicators of pain and discomfort, suggesting an underlying medical condition.
Medical & Psychiatric Conditions Among Adults with ASD

- Gastrointestinal Disorders: 24% higher
- Hypertension: 42% higher
- Diabetes: 50% higher
- Obesity: 69% higher
- Sleep Disorders: 90% higher
- Anxiety: 117% higher
- Depression: 123% higher
- Suicide Attempts: 433% higher

Figures as compared to adults without ASD.

Image courtesy Lisa Croen, Kaiser Permanente Division of Research
Something wise to keep in mind when you see a patient with autism . . .

“Clinicians should expect individuals with autism to experience medical issues in the same frequency as their non-affected peers.”

*Pediatrics* 2010; 125;S1.

Timothy Buie, MD - Director of Pediatric Gastroenterology and Nutrition, Lurie Center for Autism; Massachusetts General Hospital for Children and Harvard Medical School
Autism: Original disease description:

6/11 Cases described below have common issues . . .

What do these cases have in common?

What underlying medical issues or conditions come to mind?

- GER
- Food allergies
- Feeding problems
Sensory processing deficits (SPDs) in autism that may affect feeding

A person with SPD finds it difficult to process and act upon information received through the senses and turn them into appropriate motor and behavioral responses.

- Neurological “traffic jam”
- Creates challenges in performing everyday tasks
- Motor clumsiness, behavioral problems, anxiety, depression, school failure, and feeding difficulties

What **additional problem** is more likely to occur in children with autism compared to typically developing children?

  - Food selectivity—beyond “picky”
  - Food refusal
  - Oral sensory defensiveness
  - Behavioral rigidity

- **Children with ASD have more feeding problems and food selectivity compared to their peers**
Have you considered the child’s motor skills?

- Are often overlooked
- “Look beyond the mouth”
  - Assess motor skills – low skills more difficult to self-feed
- A reason for food refusal may be because the food is too difficult to manage
- Restricted diet limits opportunity to progress motor skills
  - Eg., if you only eat purees, you might not have the experience to have learned how to chew food with a greater texture
Motor skill assessment and intervention

- **Assessment:** look at child’s food choices
  - What are the preferred vs. most effective food textures?
  - Monotonous, limited diet
    - Color, shape, integrity, textures, temperature etc.
  - Environment: location-specific eating; noise, smell, visual

- **Intervention:**
  - **Collaboration:** RDs working with OT/SLP - align their recommendations so child receives the most effective textures
  - Evaluate the whole body posture and positioning
  - Recommendations need to adapt to child’s individual profile
Odyssey of GI issues and Autism

Evaluation, Diagnosis, and Treatment of Gastrointestinal Disorders in Individuals With ASDs: A Consensus Report
Pediatrics 2010;125:S1
DOI: 10.1542/peds.2009-1878C

Recommendations for Evaluation and Treatment of Common Gastrointestinal Problems in Children With ASDs
Timothy Buie, George J. Fuchs, III, Glenn T. Furuta, Koorosh Kooros, Joseph Levy, Jeffery D. Lewis, Barry K. Wershul and Harland Winter
Pediatrics 2010;125:S19-S29
DOI: 10.1542/peds.2009-1878D

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://www.pediatrics.org/cgi/content/full/125/Supplement_1/S19
What problems are more likely to occur in children with autism compared to typically developing children?

3.2-fold increase in odds of having **GI issues**

4 most common symptoms:
1. Diarrhea
2. Constipation
3. Reflux
4. Abdominal pain

GI Disorders in Children with ASD – Overall Prevalence: 9 – 91%

<table>
<thead>
<tr>
<th>Objective Signs/Symptoms</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constipation</td>
<td>6-45%</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>3-77%</td>
</tr>
<tr>
<td>Belching/Vomiting</td>
<td>5-30%</td>
</tr>
<tr>
<td>Flatulence</td>
<td>2-41%</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Reported-suspected Signs/Symptoms</th>
<th></th>
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<tbody>
<tr>
<td>Abdominal pain or discomfort</td>
<td>?</td>
</tr>
<tr>
<td>Enteric infections (dysbiosis)</td>
<td>?</td>
</tr>
<tr>
<td>Gastritis (requires EGD)</td>
<td>?</td>
</tr>
<tr>
<td>Gastroesophageal reflux (requires an EGD)</td>
<td>?</td>
</tr>
<tr>
<td>Lactose intolerance</td>
<td>?</td>
</tr>
<tr>
<td>Leaky gut</td>
<td>?</td>
</tr>
<tr>
<td>Maldigestion</td>
<td>?</td>
</tr>
<tr>
<td>Malabsorption</td>
<td>?</td>
</tr>
</tbody>
</table>

GI issues in ASD are common and parent-reported concerns correlate well with physician assessment.

# Medical Issues: GI and Autism

<table>
<thead>
<tr>
<th>Findings</th>
<th>References</th>
</tr>
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</table>
## Traditional vs. unconventional symptom recognition

<table>
<thead>
<tr>
<th>Typical Child</th>
<th>Autism/Non-Verbal Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hurts to swallow</td>
<td>Intermittent or continuous tantrum, feeding refusal</td>
</tr>
<tr>
<td>Hard to swallow</td>
<td>Banging on chest, textural preferences</td>
</tr>
<tr>
<td>Something stuck in throat</td>
<td>Pointing to throat, tapping site of distress</td>
</tr>
<tr>
<td>Have heartburn</td>
<td>Irritability after meals or at bedtime; poor sleep patterns</td>
</tr>
<tr>
<td>Stomach hurts after eating</td>
<td></td>
</tr>
<tr>
<td>Reports pain</td>
<td>Self-injury, aggression</td>
</tr>
</tbody>
</table>
New symptom development think medical/GI issues
**Evaluation, Diagnosis and Treatment of GI Disorder in Individuals with ASDs: A Consensus Report**

Buie et al. *Pediatrics* 2010; 125; S1.

**TABLE 6 Key Take-Away Messages**

<table>
<thead>
<tr>
<th>Message</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individuals with ASDs whose families report gastrointestinal symptoms warrant a thorough gastrointestinal evaluation.</td>
</tr>
<tr>
<td>All of the common gastrointestinal conditions encountered by individuals with typical neurologic development are also present in individuals with ASDs.</td>
</tr>
<tr>
<td>The communication impairments characteristic of ASDs may lead to unusual presentations of gastrointestinal disorders, including sleep disturbances and problem behaviors.</td>
</tr>
<tr>
<td>Caregivers and health care professionals should be alert to the presentation of atypical signs of common gastrointestinal disorders in patients with ASDs.</td>
</tr>
<tr>
<td>If a person with an ASD is on a restricted diet, professional supervision can help to identify and treat nutritional inadequacy.</td>
</tr>
</tbody>
</table>
What problems are more likely to occur in children with autism compared to typically developing children?

- 2.2-fold increase in odds of having food allergies

Food Allergies

“Food allergy” refers to adverse immunologic reactions to food

Usually IgE-mediated

Both acute reactions (hives and anaphylaxis) and chronic disease (asthma, atopic dermatitis) and gastrointestinal disorders like Eosinophilic Esophagitis (EoE) may be caused or exacerbated by food allergy

<table>
<thead>
<tr>
<th>TARGET ORGAN</th>
<th>IGE-MEDIATED DISORDER</th>
<th>NON-IGE-MEDIATED DISORDER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skin</td>
<td>Urticaria and angioedema</td>
<td>Atopic dermatitis</td>
</tr>
<tr>
<td></td>
<td>Atopic dermatitis</td>
<td>Dermatitis herpetiformis</td>
</tr>
<tr>
<td>Gastrointestinal tract</td>
<td>Oral allergy syndrome</td>
<td>Proctocolitis</td>
</tr>
<tr>
<td></td>
<td>Gastrointestinal “anaphylaxis”</td>
<td>Enterocolitis</td>
</tr>
<tr>
<td></td>
<td>Allergic eosinophilic gastroenteritis</td>
<td>Allergic eosinophilic gastroenteritis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enteropathy syndrome</td>
</tr>
<tr>
<td>Respiratory tract</td>
<td>Asthma</td>
<td>Heiner syndrome</td>
</tr>
<tr>
<td></td>
<td>Allergic rhinitis</td>
<td></td>
</tr>
<tr>
<td>Multisystem</td>
<td>Food-induced anaphylaxis</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Food-associated, exercise-induced anaphylaxis</td>
<td></td>
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</tbody>
</table>
“Children with ASD can be difficult to examine, often due to poor cooperation and difficult office behavior. In addition, many ASD individuals are nonverbal or hypo- verbal, and many of these patients have deficits in sensory processing, which are features that prevent them from reporting pain or accurately localizing discomfort.”

Restricted diets are common in children with autism, especially in those with Gastrointestinal Issues and Food Allergies

Parents often initiate unproven biological-based therapies—herbs, vitamins, and supplements\(^1\)-\(^3\)

Most frequent parent-initiated diet is the gluten-free, casein-free diet\(^3\)-\(^6\)

Children with autism often exhibit idiosyncratic food choices/food selectivity and rigid behaviors and have a 5.1 greater odds of feeding problems compared to typically developing peers\(^7\)-\(^9\)

Specific antigen removal is a recommended management strategy for:

- GI conditions (E.g., EoE, GERD)\(^10\),\(^11\)
- Food allergies\(^12\),\(^13\)

<table>
<thead>
<tr>
<th>Three reasons why restricted diets are common in autism:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Parent directed</td>
</tr>
<tr>
<td>• Parents often initiate unproven biological-based therapies—herbs, vitamins, and supplements(^1)-(^3)</td>
</tr>
<tr>
<td>• Most frequent parent-initiated diet is the gluten-free, casein-free diet(^3)-(^6)</td>
</tr>
<tr>
<td>2. Child self restricts</td>
</tr>
<tr>
<td>• Children with autism often exhibit idiosyncratic food choices/food selectivity and rigid behaviors and have a 5.1 greater odds of feeding problems compared to typically developing peers(^7)-(^9)</td>
</tr>
<tr>
<td>3. Healthcare Professional initiated</td>
</tr>
</tbody>
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What may occur if diet is restricted?

- Restrictions may lead to **nutritional deficiencies** and **malnutrition**
  - Macro- and micro-nutrient deficiencies:
  - **Protein**, iron, vitamins A, B\textsubscript{12}, D, niacin, calcium, folate, zinc

Although normal growth is important, it may not equate to adequate nutritional intake in autism

RDs need to wear many hats . . .

"Extra" assessment considerations:

1. Detailed histories: GI issues, feeding patterns, food allergy/intolerances, family (medical history, caregivers)

2. Detailed physical assessment: Bowel habits and patterns, skin, sleep habits, pain/discomfort (aggressive or self-injury)

3. Behavioral pattern (including feeding behaviors)

4. Detailed diet history: nutritional adequacy; Establish a baseline for determining effectiveness of dietary change

5. Inquire as to who is involved in the child’s care
   • Therapists, school personnel, WIC RDs, physicians (all disciplines)

CONSULT AS NECESSARY AND COLLABORATE ALWAYS
Nutritional maladies in ASD

Fried-potato diet causes vitamin A deficiency in an autistic child.

Tanoue K¹, Matsui K, Takamatsu T.

Scurvy in an autistic child: MRI findings.

Gonqidi P¹, Johnson C, Dinan D.

Nutritional implications of selective eating in a child with autism spectrum disorder.

Keown K¹, Bothwell J, Jain S.

Vitamin B12 optic neuropathy in autism.

Pineles SL¹, Avery RA, Liu GT.

Symptomatic nutritional rickets in a teenager with autistic spectrum disorder.

Stewart C², Latif A.

A case of scurvy in an autistic boy.

Monks G¹, Juracek L, Weigand D, Magro C, Cornelison R, Crowson AN.

Fast food fried chicken; Deficiencies B vitamins, thiamine, pyridoxine

>2.5 L Carrot Jc/day; elevated serum carotene and Vit D deficiency
“Individuals with ASD deserve the same thoroughness and standard of care in the diagnostic workup and treatment of GI concerns as should occur for patients without ASD.”

Bill of Rights for Individuals with Autism

Evaluation, Diagnosis, and Treatment of Gastrointestinal Disorders in Individuals with ASDs: A Consensus Report
Buie T et al. Pediatrics 2010;125;S1
**Summary: Key recommendations for HCPs caring for children with ASD**

In clinical settings, healthcare providers should:

1. Include assessment of feeding problems and nutrient intake as part of early routine medical evaluations.

2. Not rely exclusively on typical anthropometrics (HT, WT, BMI) to assess overall heath status.

3. Educate parents/caregivers regarding potential empirical, detrimental non-proven interventions.

4. Refer to a Registered Dietitian/Nutritionist to guide dietary intervention strategies.

5. Assess for potential under/over supplementation.

6. Foster interdisciplinary collaboration and communication to help improve the level of care provided.

7. Consider increased risk for diet-related chronic diseases that may develop in adulthood.
Summary:

1. Understand diagnostic criteria for ASD and its prevalence.

2. Recognize the unusual manifestations of GI issues in hypo- or non-verbal children with autism and how they may be identified.

3. Recognize primary contributors to nutritional deficits in children with ASD including: Feeding problems, GI issues and food allergies.

4. Describe commonly occurring nutritional deficits that have been reported in children with ASD.