Assessment and Treatment of Feeding Problems in Children with ASD

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Learning Objectives

- Describe food selectivity and related mealtime concerns in ASD
- Identify medical outcomes and nutrition issues associated with atypical patterns of intake
- Recognize possible contributing factors, focusing on evidence of gastrointestinal (GI) concerns in ASD
- Identify appropriate interventions for feeding disorders in ASD based on the severity of the presenting problem. This includes parent consultation/education, nutritional guidance, behavioral therapy, medical interventions, and intensive inpatient services.

Autism Spectrum Disorder (ASD)

• DSM – 5:

Neurodevelopmental disorder(s) of unknown genetic origin where symptoms unfold over the first few years of life:

- Persistent deficits in social communication and social interaction
- -Restrictive, repetitive patterns of behavior, interests, or activities

Volume: Associated Factors

- Medical Issues:
 - Congenital or acquired respiratory, cardiac, and gastrointestinal problems, which cause difficult or painful eating experiences
- These include:
 - Gastroesophageal reflux
 - Food allergies
 - Gastroenteritis
 - Dysmotility
 - Prematurity (with intubation)
 - Bronchopulmonary dysplasia
 - Short bowel syndrome
 - Lactose intolerance
- Feeding problems occurs in 40-70% of children with chronic medical conditions (Lukens & Silverman, 2014)

Variety: Associated Factors

• Autism Spectrum Disorder (ASD)

Pediatric Feeding Disorders

- Chronic feeding concerns generally involve either:
 - 1) Volume Food Refusal
 - 2) Variety Food Selectivity

Severe problem behaviors during meals:

- Crying
- Disruptions
- Elopement
- Aggression
- Spitting
- Expulsion



Historical Background



- Kanner, L. (1943). Autistic disturbances of affective contact. *The Nervous Child*, 2, 217-250.
- "Food is the earliest intrusion that is brought to the child from the outside world."

Research Support

- Ledford & Gast (2006)
 - Most comprehensive summary at the time
 - 7 descriptive studies identified
 - N = 381 children with ASD
- Estimates ranged from <u>46% and 89%</u> of children with ASD displaying significant feeding problems
 - Often no identifiable organic precursor

Research Support

- Limitations
 - No control group and mostly descriptive studies
 - Involved biased clinical sample e.g., feeding disorders clinic
 - Lack of uniformity definition of feeding problem

ORIGINAL PAPER

Feeding Problems and Nutrient Intake in Children with Autism Spectrum Disorders: A Meta-analysis and Comprehensive Review of the Literature

William G. Sharp · Rashelle C. Berry · Courtney McCracken · Nadrat N. Nuhu · Elizabeth Marvel · Celine A. Saulnier · Ami Klin · Warren Jones · David L. Jaquess

- Inclusion criteria:
- 1. Published between 1980 and 2011
- 2. Focused on pediatric population (birth to 18 years)
- 3. Involved a comparison group
- 4. Evaluated feeding and/or nutrition in ASD a standardized, replicable manner
- 5. Presented data either descriptively (e.g., frequency, percentages) or statistically (e.g., t scores)
- Exclusion criteria:
- 1. Studies with known sampling bias (e.g., chart reviews from feeding programs)
- 2. Studies focusing on dietary manipulation (e.g., GFCF



Fig. 1 Flow diagram of included and excluded studies

ASD versus subgroup	Number of	Random effect	s model		Within-gro	Within-groups			
	contributing studies	SMD (SE)	SMD (SE) OR 95 % confidence limits		p value	χ^2 test (Q)	p value		
				LCL	UCL				
All groups	15	0.89 (0.08)	5.11	3.74	6.97	< 0.001			
TD	13	0.94 (0.11)	5.49	3.77	7.98	< 0.001	29.9	0.003	
SB	3	0.98 (0.22)	5.89	2.73	12.71	< 0.001	0.45	0.798	
DD	2	0.67 (0.19)	3.36	1.69	6.67	0.001	0.012	0.913	

Table 4 Effect sizes, 95 % confidence limits and within-group tests for heterogeneity for studies included in the meta-analysis for feeding behavior problems by comparison groups

TD typically developing, DD other developmental delay, SB siblings

<u>Fivefold</u> increase in the odds of having a feeding problem in ASD

Food Selectivity

Preference - carbohydrates, snacks, fats, and/or processed food Rejection - fruits and vegetables

Sharp et al (2013). Feeding Problems and Nutrient Intake in Children with Autism Spectrum Disorders: A Meta-analysis and Comprehensive Review of the Literature. *Journal of Autism and Developmental Disorders*, 43(9): 2159 - 2173.

Picky Eating vs. Food Selectivity

Food selectivity in ASD is distinct from picky eating in terms of <u>duration</u> and <u>intensity</u>

- **Duration** Food selectivity is a chronic concern that persists overtime
 - Suarez, Nelson, and Curtis (2013) indicated no change in food selectivity in 52 children with ASD over a 20-month period.
- Intensity Food selectivity more likely to involve strong refusal behaviors (e.g., crying, throwing objects, aggression)

Food Selectivity vs. Picky Eating



Figure 1: Life span model of food neophobia as proposed by Dovey et al. (2008)

Table 5 Effect sizes, 95 % confidence limits and within-group tests for heterogeneity for studies included in the meta-analysis for nutritional data

Nutrient	Number of	Random effects m	dom effects model						
	contributing studies	SMD (SE)	OR	95 % confide	p value				
				LCL	UCL				
Calcium	8	-0.65 (0.29)	0.31	0.11	0.85	0.022			
Carbohydrates	7	-0.02 (0.07)	0.97	0.76	1.24	0.810			
Energy	6	0 (0.06)	0.99	0.80	1.25	0.995			
Fiber	6	0.09 (0.12)	1.18	0.77	1.78	0.448			
Iron	7	0.17 (0.20)	1.35	0.66	2.76	0.414			
Protein	7	-0.58 (0.25)	0.35	0.14	0.86	0.021			
Total fat	6	0.03 (0.06)	1.05	0.84	1.30	0.690			
Vitamin A	6	-0.51 (0.35)	0.39	0.11	1.37	0.143			
Vitamin C	7	-0.13 (0.19)	0.98	0.52	1.87	0.507			
Vitamin D	6	-0.07 (0.19)	0.88	0.45	1.71	0.703			
Vitamin E	5	0.05 (0.17)	1.10	0.61	1.98	0.742			
Zinc	6	-0.03 (0.09)	0.95	0.69	1.31	0.758			

Sharp et al (2013). Feeding Problems and Nutrient Intake in Children with Autism Spectrum Disorders: A Meta-analysis and Comprehensive Review of the Literature. *Journal of Autism and Developmental Disorders*, 43(9): 2159 - 2173.

Daily Living and Quality of Life

Increased parental stress regarding health and development

Reduced opportunities to eat at restaurants or social occasions

Disrupted family meals & further limitations in social interactions

Required to prepare multiple menus for each meal

J Dev Phys Disabil (2012) 24:19–33 DOI 10.1007/s10882-011-9252-2

ORIGINAL ARTICLE

Mothers' Challenges in Feeding their Children with Autism Spectrum Disorder—Managing More Than Just Picky Eating

Laura G. Rogers • Joyce Magill-Evans • Gwen R. Rempel

Parent Report

- "I'm worried about his health. How can he stay alive eating two foods and drinking water?"
- "If you ever saw those meltdowns you wouldn't want to offer non-preferred food either."
- "He'll gag and almost get physically sick just watching us eat something like spaghetti and meat sauce."
- "My younger children won't eat the food they don't like, but my son with autism won't even come to the table."

The Parent Experience

- Meals described as stressful, chaotic, and energy depleting
- Mealtimes lack positive interactions
- Child's food selectivity limited other family members' food choices during meals
- Caregivers reported ceasing family meals to avoid further worry, guilt, and stress.

Marquenie, K., Rodger, S., Mangohig, K., & Cronin, A. (2011); Suarez, Atchison, & Lagerwey (2016)

PEDIATRICS[®]

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Gastrointestinal Symptoms in Autism Spectrum Disorder: A Meta-analysis

Barbara O. McElhanon, Courtney McCracken, Saul Karpen and William G. Sharp *Pediatrics*; originally published online April 28, 2014; DOI: 10.1542/peds.2013-3995

Inclusion criteria:

- 1. Published between 1980 and 2012
- Focused on pediatric population (birth to 18 years)
- 3. Involved a comparison group
- 4. Evaluated GI concerns in ASD a standardized, replicable manner
- Presented data either descriptively (e.g., frequency, percentages) or statistically (e.g., t scores)

Exclusion criteria:

- 1. Studies with known sampling bias (e.g., chart reviews from GI clinics)
- Studies using a healthy control group (i.e., screening out children with known gut issues)



FIGURE 1 Flow diagram of included and excluded studies.

TABLE 1 ASD and GI Key Words Used in Database Search

ASD Search Terms Asperger's Autism Autism spectrum disorder Autistic Pervasive developmental disorder PDD-NOS GI Search Terms Abdominal pain/abdomen Celiac Colitis Constipation Diarrhea Digestion Digestive disorders/system Disaccharidase Endoscopy/colonoscopy Esophagitis/oesophagitis Gastroenterology Gastritis Gastrointestinal Gluten(s) Gastroesophageal reflux Intestines/intestinal Vomiting

PDD-NOS, pervasive developmental disorder not otherwise specified.

TABLE 4 ESs, 95% Confidence Limits, and Within-Group Tests for Heterogeneity for Studies Included in the Meta-analysis for GI Symptoms

GI Symptom	Number of Contributing Studies	r of Contributing Studies Random Effe					
		SMD (SE) Odds Ratio		95 Confi Lin	Р		
				Lower	Upper		
General GI concerns	10	0.91 (0.23)	5.25	2.34	11.75	<.0001	
Diarrhea	12	0.71 (0.19)	3.63	1.82	7.23	<.0001	
Constipation	9	0.75 (0.16)	3.86	2.23	6.71	<.0001	
Abdominal pain	8	0.49 (0.20)	2.45	1.19	5.07	.016	

McElhanon, B.O., McCracken, C., Karpen, S., Sharp, W.G. (2014) Gastrointestinal Symptoms in Autism Spectrum Disorders: A Meta-analysis. *Pediatrics*, 133:5 872-883

Other key findings

- Insufficient data to analyze data on other GI concerns, such as reflux or EOE, often link with organic pathology
- Although organic factors leading to difficult or painful eating, such as gastroesophageal reflux, gastroenteritis, and food allergies, often precipitate or play a role in the development of chronic feeding concerns in other pediatric populations, research has yet to identify a clear GI link to account for the emergence, maintenance, and topography of feeding problems associated with ASD.

Buie et al. (2010)

- All of the common gastrointestinal conditions encountered by individuals with typical neurologic development are also present in individuals with ASDs.
- The communication impairments characteristic of ASDs may lead to unusual presentations of gastrointestinal disorders, including sleep disturbances and problem behaviors.
- Caregivers and health care professionals should be alert to the presentation of atypical signs of common gastrointestinal disorders in patients with ASDs.

Clinical Implications

When a feeding concerns is present in ASD:

- An important first step when working with any child with a feeding disorder involves ruling out the potential contribution of organic factors (e.g., gastroesophageal reflux, food allergy) that may cause pain or discomfort along the GI tract.
- This may require adopting a lower threshold for obtaining subspecialty consultation (e.g. pediatric gastroenterologist; allergist) and increased reliance on objective testing in order to recognize pathology and facilitate a diagnosis given limitations in communication often observed in ASD (Buie et al., 2010)

A Measurement Problem

- 1) No universally accepted definition
- 2) High variability in item content
- 3) No direct link with actual diet and nutritional status
- 4) Food selectivity has been viewed as a monolithic construct (e.g., total number of items accepted or rejected), without consideration to symptom severity or dietary diversity.

Bandini et al. (2010)

Three Part Definition of Food Selectivity:

- 1) Food Refusal: Percentage of foods offered that the child will not eat
- 2) Limited Food Repertoire: Number of unique foods consumed over a three-day period
- 3) High Frequency Single Food Intake (HFSFI): Number of single food items eaten 4 to 5 or more times daily.

Bandini et al. (2010)

- 53 children with ASD vs. 58 typically developing children (ages 3-11 years).
- Children with ASD:
- 1) Exhibited greater food refusal (rejecting 41.7% of food items versus 18.9% rejected by peers)
- 2) Consumed a more limited dietary repertoire (consuming an average of 19 foods over a three day period vs 22.5 consumed by peers)
- HFSFI was rarely observed in both groups.

Framework for defining food selectivity by severity

Category	Criteria	Rationale
Severe Food Selectivity	Complete rejection of one or more food groups	Increases the risk of micro- and/or macronutrient deficiency (e.g., scurvy; iron deficiency anemia; kwashiorkor)
	• Accepts five or fewer total food items	Further narrowing of the diet would eliminate additional food groups
Moderate Food Selectivity	 Consumes two or fewer items in one or more food groups 	Reflects a diet that may lack diversity of nutrient-dense foods; further restriction increases likelihood of nutrient deficiency
	 Regularly (weekly) accepts at least one item across the five food groups 	Decreases likelihood of being diagnosed with a nutrient deficiency; however, intake may be limited to a handful of preferred items or involve high intake of a single food group
Mild Food Selectivity	• Diet involves at least three or more items from each good group (15 total foods); more than half of items fall into one food group	Suggests low probability of nutrient deficiency while recognizing child may show preference for a certain food group (e.g., grains)
	• Consistently (daily) accepts foods from all five food groups	Indicates the child maintains a consistent degree of dietary diversity

The Behavioral Perspective

- Why?
 - Symptom severity
 - Medical concern vs. quality of life issue
- How?
 - Severe -> Intensive Multidisciplinary Intervention
 - Moderate -> Outpatient/home interventions
 - Mild -> Adapt Existing Guidelines for Introducing Food (e.g., Ellen Satter)



The Autism MEAL Plan: A parent-training curriculum to manage eating aversions and low intake among children with autism

Autism 0(0) 1–11 © The Author(s) 2013 Reprints and permissions: sagepub.co.uk/journalsPermissions.nav DOI: 10.1177/1362361313489190 aut.sagepub.com

SAGE

William G Sharp^{1,2}, T Lindsey Burrell^{1,3} and David L Jaquess^{1,2}

ORIGINAL ARTICLE

Behavioral Parent Training to Address Feeding Problems in Children with Autism Spectrum Disorder: A Pilot Trial

Cynthia R. Johnson¹ · Emily Foldes² · Alexandra DeMand² · Maria Mori Brooks³

Parent vs. Child Perspective

- Parent
 - Experienced eater
 - Flexibility with different food types and tastes
 - Eats large portions of foods
- Child
 - Non-preferred foods are aversive/noxious
 - Preferred foods can be contaminated
 - Change in presentation and contact with non-preferred foods
 - Highly motivated to avoid contact

Involve children in the process through choice

- Food items to target
- Initial bite volume
- Jump in volume
- Which foods to add next

Designing Interventions

- Overarching philosophy:
 - Treatment involves persisting with a reasonable demand
 - In order to establish traction for behavior change, begin with "zone of likely success"
 - Can not reinforce a behavior is low probability of occurring
 - And should consider the complete tool box of antecedent and consequence based strategies
 - If only relying on consequences, may not be able to replace/override function

Other aspects of the meal.....

- Increase structure and routine:
 - Regular meal/snack schedule
 - Meals involve a table with age appropriate seating
- Differential Attention
 - Provide attention and praise for appropriate mealtime behaviors-
 - Accepting bites, swallowing, eating properly with a spoon, trying a new food, or staying seated throughout the meal
 - Ignore minor behavior problems
 - Whining, negative statements regarding food, messy eating (if age appropriate)

General Behavioral Concepts

Treatment must involve:



Levels-

- Ignoring negative statements
- Non-removal of the plate/spoon

Exposure with Response Prevention



Types-

- Praise and attention
- Access to preferred activities
- Consumption of preferred food
- Escape / break Marcus Autism Center

Decision Rules

- Make sure behavior is stable across meals
 - After 3 meals with few problem behaviors, increase the demand
 - Add new food item
 - Increase bite number
 - Increase bite volume
 - Increase meal length
 - If problem behaviors persist across 2 meals, reduce the demand and break into smaller steps

Therapist Bite-by-Bite Data Sheet

Child:	Date:	Data Collector:	Feeder:
Start Time:	Stop Time:	Protocol:	Bolus size:
Pre-Session Food Weight:	Post-Session Food Weight:	Food Spill:	Food Weight Difference:

Module	Session #	Bite Number	Acc (5/>5/IVGP)	Expel (a/p)	Pack (🗸)	Mouth Clean (✓)	Gag (✔)	Cough (✔)	Emesis (✔)	CP's (४)	Negative Voc (✓)	Food	Instructions	Prompts	Consequences	
		1.														
		2.														
		3.														
		4.														
		5.														
Session Totals																
		6.														
		7.														
		8.														
		9.														
		10.														
Session Totals																

Power of Choice

- Food items to target
- Initial bite volume
- Jump in volume
- Which foods to add next

Food	¼ pea	½ pea	Pea	2 pea	½ level	level	heaping
Strawberry							
Rice							
Carrots			000				
Rawberry gogurt							
Waffle							
String cheese			000				
Strawberry yogurt							
Wheat bread			000				
Blueberry yogurt			000				

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What Is Known

1) Food selectivity is primarily an issue of poor dietary diversity; compromised growth is less likely. Associated sequela may include vitamin and mineral deficiencies, decreased quality of life for families and increased risk for childhood obesity.

2) Nutritional monitoring – including serum testing of vitamin levels in cases of severe food selectivity –should be included as part of routine health screening to detect possible underlying nutritional insufficiencies

3) GI symptoms (e.g., constipation, diarrhea) are prevalent in children with ASD; however, the relationship between possible GI dysfunction and food selectivity remains unknown.

4) Degree of dietary restriction in ASD ranges from mild to severe. Children with severe food selectivity are at risk for severe malnutrition (e.g., scurvy, rickets), while mild food selectivity more closely resembles "pickiness" often observed in young children.

5) Behavioral intervention is the only well-established treatment for food selectivity in ASD, although optimal care should involve contributions from a multidisciplinary team to screen for possible dietary, oral-motor, and/or medical concerns.

Questions?



References - Feeding

- Bandini, L.G., Anderson, S.E., Curtin, C., Cermak, S., Evans, E.W., Scampini, R., Maslin, M., & Must, A. (2010). Food selectivity in children with autism spectrum disorders and typically developing children. *The Journal of Pediatrics*, 157 (2), 259 264.
- Buie T., Campbell, D.B., Fuchs, G.J., Furuta, G.T., Levy, J., Vandewater, J., et al. (2010). Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report. *Pediatrics*, 125(suppl 1), S1-18.
- Curtin C, Anderson SE, Must A, Bandini L. The prevalence of obesity in children with autism: a secondary data analysis using nationally representative data from the National Survey of Children's Health. BMC Pediatr. 2010 Feb 23;10:11. doi: 10.1186/1471-2431-10-11.
- Egan AM, Dreyer ML, Odar CC, Beckwith M, Garrison CB. Obesity in young children with autism spectrum disorders: prevalence and associated factors. *Child Obes.* 2013; doi: 10.1089/chi.2012.0028. Epub 2013 Mar 13
- Emond, A., Emmett, P., Steer, C., Golding, J. (2010). Feeding symptoms, dietary patterns, and growth in young children with autism spectrum disorders. *Pediatrics*, 126 (2), 337 342
- Ho, Eaves, & Peabody (1997). Nutrient Intake and Obesity in Children with Autism. Focus on Autism and Other Developmental Disabilities, 12 (3), 187 192.
- Johnson, C.R., Handon, B.L., Mayer-Costa, M., & Sacco, K. (2008). Eating habits and dietary status on young children with autism. *Journal of Autism and Developmental Disorders*, 20, 437 448.
- Kanner, L. (1943). Autistic disturbances of affective contact. The Nervous Child, 2, 217–250.
- Ledford, J.R. & Gast, D.L. (2006). Feeding problems in children with autism spectrum disorders: A review. *Focus on Autism and Other Developmental Disabilities*, *21*, 153-166.
- Lukens, C.T. & Linscheid (2008). Development and validation of an inventory to assess mealtime behavior problems in children with autism. *Journal of Autism and Developmental Disorders*, 38, 342 352.
- Lukens, C.T. & Silverman, A.H. (2014). Systematic Review of Psychological Interventions for Pediatric Feeding Problems. Journal of Pediatric Psychology. pp. 1–15, 2014 doi:10.1093/jpepsy/jsu040
- Manikam, R., & Perman, J. (2000). Pediatric feeding disorders. *Journal of Clinical Gastroenterology*, *30*, 34-46.
- Martins, Y., Young, R.L., & Robson, D.C. (2008). Feeding and eating behaviors in children with autism and typically developing children. *Journal of Autism and Developmental Disorders*, 38, 1878 1887.
- Mayes, L., & Volkmar, F. (1993). Nosology of eating and growth disorders in early childhood. *Child and Adolescent Psychiatric Clinics of North America*, *2*, 15-25.

References - Feeding

- McElhanon, B.O., McCracken, C., Karpen, S., Sharp, W.G. (2014) Gastrointestinal Symptoms in Autism Spectrum Disorders: A Meta-analysis. *Pediatrics*, 133:5 872-883.
- Satter, E. (1990). The feeding relationship: Problems and interventions. Journal of Pediatrics, 117(2 Pt 2), S181–S189.
- Schmitt, L., Heiss, C.J., & Campbell, E.E. (2008). A comparison of nutrient intake and eating behaviors of boys with and without autism. *Topics in Clinical Nutrition*. 23(1), 23 31.
- Sharp, W.G., Berry, R.C., McCracken, C., Nuhu, N.N., Marvel, E., Saulnier, C.A., Klin, A., Jones, W., & Jaquess, D.L. (2013). Feeding Problems and Nutrient Intake in Children with Autism Spectrum Disorders: A Meta-analysis and Comprehensive Review of the Literature. *Journal of Autism and Developmental Disorders*, 43(9): 2159 - 2173.
- Sharp, W. G., Jaquess, D. L., Morton, J. S., & Herzinger, C. (2010). Pediatric feeding disorders: A quantitative synthesis of treatment outcomes. *Clinical Child and Family Psychology Review*, *13*, 348-365.