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FEEDING DISORDERS IN CHILDHOOD AUTISM

by

Caitlin Etling

B.S., Southern Illinois University, 2012

A Research Paper

Submitted in Partial Fulfillment of the Requirements for the

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RESEARCH PAPER APPROVAL

FEEDING DISORDERS IN CHILDHOOD AUTISM

By

Caitlin N. Etling

A Research Paper Submitted in Partial
Fulfillment of the Requirements
for the degree of
Master of Science
in the field of Communication Disorders

Approved by:

Dr. Valerie E. Boyer

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Eating is a natural and essential human activity that is necessary to sustain life and ensure growth, but it can be a recurrent challenge for children with autism and a cause of stress for parents. Feeding difficulties have been observed and studied in children with autism spectrum disorders (ASD) extensively since the earliest understanding of the disorder, even though the presence of feeding difficulties is not used in diagnosing autism (Twachtman-Reilly, Amaral, & Zebrowski, 2008, p. 261). There is a multitude of research that has been conducted within the field regarding children with autism and feeding habits. These articles have addressed questions regarding feeding routines, refusal of certain foods, and eating behaviors of family members.

The purpose of this paper is to describe common feeding difficulties associated with the presence of autism spectrum disorder and provide guidance based on the literature for speech-language pathologists (SLPs). With a better understanding of feeding aspects that may coincide with ASD, SLPs will be better able to identify, diagnose, and treat the problem. Knowing this, the questions remain; with what types of feeding problems do children with autism present? How do speech language pathologists assess feeding? What strategies assist in facilitating feeding?

Definitions

Autism

Before these questions can be answered, it is important to define autism and what constitutes a feeding disorder. Martins, Young, and Robson's (2008) study defined the following:

Autism spectrum disorder (ASD) is a developmental disorder diagnosed in terms of its behavioral presentation. Persons with this disorder present with deficits in socialization and communication, as well as exhibiting ritualistic or stereotypical behaviors. For a diagnosis of ASD to be considered, signs of atypical development in these areas must be present before a child is three years of age.

(p.1878)

Feeding disorder

Keen's (2008) study defined the diagnostic criteria for a feeding disorder as the following:

1. Feeding disturbance as manifested by persistent failure to eat adequately with significant failure to gain weight or significant loss of weight over at least 1 month.
2. The disturbance is not due to an associated gastrointestinal or other general medical condition (e.g. esophageal reflux)

3. The disturbance is not better accounted for by another developmental disorder (e.g. Rumination Disorder) or by lack of available food.
4. The onset of a feeding disorder is before the age of 6 years. (p.210)

Signs and Symptoms

Common signs and symptoms of a feeding disorder include: poor weight gain or weight loss, feeding tube dependence, bottle or formula dependence, mealtime irritability or mealtimes exceeding 40 minutes, distress and anxiety with new foods, inability to increase or vary textures, inability or refusal to feed oneself, and extreme pickiness (Jaquess, 2009; Koeppen, 2010).

Differential Diagnosis

The term feeding disorder is not synonymous with the term swallowing disorder, commonly known as dysphagia. It is important to understand the differences between the two disorders and the SLP's role in treating feeding and swallowing disorders.

According to ASHA (n.d.), feeding disorders include problems picking up food in order to suck, chew, or swallow it. A feeding disorder may be the inability to pick up food and get it to the mouth or the inability to completely close the lips to keep food from falling out of the mouth (ASHA, n.d.). Feeding

disorders are relatively common during childhood. A feeding disorder can occur in both typically developing children and children with autism. Feeding problems are reported to occur in 25-35% of typically developing children and up to 80% of children with a developmental delay, such as ASD (Keen, 2008, p. 209).

Dysphagia, on the other hand, consists of problems that can occur at different stages in the swallowing process. It can occur at the oral phase, the pharyngeal phase, or the esophageal phase. The oral phase includes sucking, chewing, and moving food or liquid towards the throat. The pharyngeal phase includes initiating the swallow, squeezing food down the throat, and closing off the airway to prevent aspiration. The esophageal phase involves the relaxing and tightening of the openings at the top and bottom of the esophagus and squeezing food through the esophagus into the stomach (ASHA, n.d.).

SLP's Role

The SLP may work as part of a feeding team when evaluating and treating children with a suspected problem. Team members may include an occupational therapist, a physical therapist, a physician, a nurse, a dietitian or nutritionist, and a developmental specialist (ASHA, n.d.). Members of the feeding team may recommend any of the following: medical intervention, direct feeding therapy, nutritional changes, increasing

acceptance of new foods or textures, food temperature and texture changes, postural or positioning changes, behavior management techniques, or a referral to other professionals such as a psychologist or dentist (ASHA, n.d.).

ASHA (n.d.), states that the SLP's focus during intervention for feeding and swallowing disorders include: making the muscles of the mouth stronger, increasing tongue movement, improving chewing, increasing acceptance of different foods and liquids, improving sucking and drinking ability, coordinating the suck-swallow-breath pattern for infants, and altering food textures and liquid thickness to ensure safe swallowing.

Sensory Processing Disorder (SPD), Feeding, and Autism

Feeding disorders seen in autism are often a result of a sensory processing disorder. Dobbins, Sunder, and Soltys (2007) defines SPD and how it affects children with the disorder:

Sensory processing is the interpretation and organization of sensory input. It enables the child to form a response. Abnormalities in sensory processing can cause a spectrum of deficits, ranging from insignificant eccentricity to devastating dysfunction. Many people have problems with sensory processing; often, these are fairly insignificant. However, if abnormalities cause distress and dysfunction, one is

considered to have SPD. Certain patterns of pathological sensory processing have been described. Symptoms in children with SPDs may appear to be very inconsistent, fluctuating hour-to-hour, or even combining over-responsivity in one area with under-responsivity in another. It is estimated that 5% to 15% of the general population has some type of SPD severe enough to warrant intervention (pp. 14-18).

Feeding disorders, as a result of a sensory processing disorder, affect a child's ability to properly function at home, in school, and other social settings. This inability to appropriately function has an impact on physical, social, and psychological development (Jaquess, 2009).

Most researchers believe that children with autism that have a sensory processing disorder may be hypersensitive to foods, hyposensitive to foods, or a combination of the two (Koeppen, 2010). The hypersensitive child may experience tastes, textures, temperatures, and smells to a degree that is not perceived by most others. For example, the smell and texture of grilled chicken may provoke an unpleasant sensory response that is unbearable for an individual with hypersensitivity (Koeppen, 2010). The hyposensitive child may seek out strong flavors and crunchy textures to compensate for experiences they are missing. They may like spicy food, sour flavors, or only crunchy textures

(Koeppen, 2010). Food choices are based on the individual's sensory experiences. Obviously, foods that provide a favorable sensory experience will be selected over those that provide a poor sensory experience. These limited food preferences can make food selection a challenge for the individual and family members (Koeppen, 2010).

Feeding problems in autism vs. typically developing children

Parents of children with typical development may have to address mild feeding problems at some point in their child's development, but parents of children with autism may need much more support as their child's feeding problems can be much more severe (Morris, 2008). Compensation techniques for these feeding issues in children with autism versus typically developing children will usually need to be different as well. For example, withholding food from a picky eater, until the child is hungry enough to eat is often a strategy used by the parents, even though it is not always the best option. However, for a child with autism, such a strategy could be dangerous to the child's health due to health complications that often coincide with the disorder. Picky eating is greatly complicated by the autism spectrum due to sensory issues. (Morris, 2008).

Schreck, Williams and Smith (2004) compared the eating behaviors of children with autism to typically developing children. The study was carried out by distributing

questionnaires to caregivers of children with autism or typically developing children between the ages of five and 12 years. The sample included 138 caregivers of children with autism and 298 caregivers of typically developing children (pp. 433-435).

There were two parts to the questionnaire: The Children's Eating Behavior Inventory, which evaluated mealtime behaviors and eating behaviors on a five-point scale and The Food Preference Inventory, which indicates which type of foods the child prefers and from what food group. Caregivers of children with autism reported that their children have considerably more feeding problems than caregivers of typically developing children reported. Also, children with ASD ate significantly fewer foods from each of the five food groups than children without autism and parents reported that children with autism ate only a narrow variety of presented foods. However, this finding of food selectivity was not present in the family members of the children with autism, they sustained healthy eating habits. The results of the study indicated that children with autism had a tendency to refuse more foods than children without autism, and to only accept foods of low texture. Finally, the research suggested that children with autism required specific utensils to eat with and particular food

presentations more often than typical developing children (Schreck, Williams, & Smith, 2004, pp. 433-437).

These findings, regarding the occurrence of feeding difficulties and types of feeding problems in children with ASD, are consensual among numerous research articles. Researchers have used this knowledge as a solid foundation to investigate further on the topic of feeding difficulties in autism.

Martins, Young, and Robson (2008) identified the types and frequency of feeding and eating difficulties experienced by children with autism and typically developing children with focus on the relationship between severity of autism and severity of feeding deficits. They also examined the relationship between parents' attempts to control their child's eating habits and the eating and feeding behaviors exhibited by the child with autism (pp. 1878-1882).

Martins et al. (2008) used questionnaires delivered to mothers of either typically developing children or children with autism spectrum disorder. These questionnaires were used to collect data about their own and their child's feeding and eating behaviors. In families with children with autism, mothers also completed questionnaires for typically developing siblings, if present. The sample included 41 children with ASD, 14 siblings of children with ASD, 41 typically developing children, and 82 mothers. The questionnaire package included the Eating

Behaviors Questionnaire which assessed the child's overall approach to eating and feeding, the Behavioral Pediatric Feeding Assessment Scale (BPFAS)-Problem Index Section which identified a range of eating and feeding behaviors observed in children, the BPFAS-Parent Section which evaluated parents emotions and strategies when dealing with their child's eating behaviors, the Food Neophobic Scale which assessed individuals trait level of food neophobia (i.e., fear of trying unfamiliar foods), the Childhood Autism Rating Scale which measured the participants autistic characteristics, and finally the Vineland Adaptive Behavior Scales-Interview Edition which evaluated personal and social sufficiency of individuals from birth to adult (pp. 1878-1882).

The results of this study suggested that children with autism had poorer self-feeding skills. In addition, they were slightly more likely to avoid certain foods and exhibit neophobic eating behaviors than their typically-developing peers (Martins, Young, & Robson, 2008, pp. 1883-1887). Children with ASD had more control over their eating habits than typically developing children and mothers of children with autism had greater emotional responses and behavioral control practices compared to mothers of typically developing children. Results also indicated that as the severity of the child's autism increased, parent's ability to control their child's feeding

behaviors decreased. Among children with ASD, severe impairments in the ability to adapt to change were associated with increased avoidance of foods, ritualistic eating behaviors, and picky eating behaviors. Finally, the study showed that more severe sensory impairments were associated with increased ritualistic eating behaviors and greater parental emotional responses and behavioral control practices (Martins, Young, & Robson, 2008, pp. 1883-1887).

Although questionnaires can provide researchers with valuable and useful information, it is difficult to evaluate studies based solely on survey research because subject selection procedures are often unclear and third-party reports are often inaccurate (Ahearn, Castine, Nault, & Green, 2001, p. 506). Nevertheless, it appears that feeding problems are quite common in children with autism spectrum disorder (Ahearn, Castine, Nault, & Green, 2001, p. 506).

Physical ailments resulting in feeding disorders

Feeding disorders in children with autism may be a result of physical ailments that provide an unpleasant experience. Morris (2008) estimated that up to 50% of children with autism experience gastrointestinal (GI) tract problems, ranging from mild to moderate degrees of inflammation in both the upper and lower intestinal tract, resulting in a great deal of discomfort. Excessive constipation, or encopresis, is also often commonly

associated with developmental disorders in children (Morris, 2008). These ailments are often difficult to resolve, especially in children with behavioral and communication problems inherent in ASD. When children experience discomfort preceding a meal, they may associate the pain with the food just consumed. This association may in turn result in an aversion to food (Morris, 2008).

Specialized diets

Concern regarding gastrointestinal issues has led some families to use specialized diets with their children that have autism spectrum disorder, including the gluten-free casein-free diet, the Feingold Diet, and the Specific Carbohydrate Diet (Morris, 2008).

The gluten-free casein-free diet is the most commonly known diet used to treat symptoms associated with ASD (*The gluten-free, casein-free diet for autism spectrum disorders*, 2011). Gluten proteins are found in wheat and other grains. Casein is a protein found in milk and foods containing milk. According to one theory, some individuals with autism spectrum disorders cannot properly digest gluten and casein, which form peptides, or substances that resemble opiates in their bodies (*The gluten-free, casein-free diet for autism spectrum disorders*, 2011). The peptides then change the person's behavior, perceptions, and responses to their environment. Some scientists believe that

peptides trigger an unusual immune system response in certain people (*The gluten-free, casein-free diet for autism spectrum disorders*, 2011). The gluten-free casein-free diet has not gained widespread acceptance in the medical community. Studies of the diet have had mixed results. One recent study found behavioral improvements in children on a gluten-free casein-free diet, while another study found no significant effects from the diet (*The gluten-free, casein-free diet for autism spectrum disorders*, 2011).

Another popular diet, the Feingold Diet, claims that it can improve behavior for several disorders, including ASD. The Feingold Diet requires complete removal of all synthetic dyes, flavors, preservatives, and sweeteners from a child's diet. The removal of these artificial additives is thought to lead to improvements in behavior such as reduced hyperactivity, impulsivity, frustration, aggression and irritability (Elizabeth, 2011). Improvements in the ability to learn, improved attention, memory, comprehension, and fewer physical symptoms are also claimed to be the result of this dietary intervention (Elizabeth, 2011).

The Specific Carbohydrate Diet is yet another diet that is gaining a lot of interest among families of children with autism spectrum disorders (Lewis & Seroussi, 2011). The Specific Carbohydrate Diet is based on the idea that limiting a person's

diet to simple sugars will give the body a chance to dispose of toxic chemicals in the gastrointestinal tract and restore intestinal and immune function. The Specific Carbohydrate Diet eliminates starches and most sugars and consists mainly of meats, fish, eggs, vegetables, fruits, nuts, and seeds. Some parents of children with autism who have tried the Specific Carbohydrate Diet have reported relief from symptoms like diarrhea and constipation. Some significant behavioral improvements have also been reported (Lewis & Seroussi, 2011).

Research and parent reports on diet interventions have provided unreliable evidence regarding their effectiveness. This information suggests there is no one approach that will work for everyone. However, research has suggested that treatments of gastrointestinal tract problems have led to some improvements in the symptoms of autism, including behavior, communication and social skills (Morris, 2008).

Assessment

Assessment of children with feeding disorders involves significantly more considerations than a simple clinical observation of feeding (Arvedson, 2008, p. 118). Underlying etiologies or diagnoses must be identified and defined to every extent possible because treatment will vary according to history and current status (Arvedson, 2008, p. 118). An interdisciplinary team approach allows for an organized and

comprehensive assessment through team collaboration. The main assessment goal is for every child to receive adequate nutrition and hydration without health complications and with no stress to the child or caregiver (Arvedson, 2008, p. 118).

Medical, behavioral, and environmental factors, including sensory problems, must be taken into account when feeding and eating problems occur in young children. Medical assessments should include an oral mechanism examination, swallowing evaluation, assessment of food sensitivities and allergies, medications and their effect on appetite, and a profile of the child's diet and resulting nutritional issues (Morris, 2008). A multi-disciplinary approach is common when assessing feeding and eating problems. The multi-disciplinary team involved in a feeding assessment often consists of occupational therapists, speech-language pathologists, nutritionists, doctors, and nurses (Morris, 2008).

Ahearn, Castine, Nault and Green (2001) carried out a study known as *An assessment of food acceptance in children with autism or pervasive developmental disorder-not otherwise specified*, which was an organized reproduction of the Munk and Repp (1994) investigation. This study was intended to provide an objective evaluation of the prevalence or nature of feeding patterns displayed by children with autism. Munk and Repp (1994) developed procedures for classifying feeding problems of

individuals with physical or developmental disabilities through direct observation. Their assessment consisted of food presentations from four food groups and three food textures. Acceptance or rejection of each food presentation was recorded. Categories described following assessment included food refusal, food-type selectivity, and food-texture selectivity (p.506).

Ahearn et al. (2001) reported on 30 participants in their study ranging in age from three to fourteen. All of the participants were diagnosed with either autism (21 children) or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) (9 children). Each participant's feeding behavior was assessed during six sessions using a self-feeding format (food was presented on a utensil that was placed on a plate and the child fed himself or herself). Foods were selected from four categories: fruit, vegetable, starch, and protein (pp. 506-507).

Food acceptance was defined as picking up food with or without using a spoon, opening the mouth, and placing food in the mouth within five seconds of verbal instruction. Food expulsion was noted if food appeared outside the lips after food had been accepted, such as spitting food out of the mouth, pulling food out of the mouth, or tilting the head to allow food to spill out of the sides of the mouth. A disruption was defined as any adverse behavior that interrupted the presentation of food (Ahearn et al., 2001, p. 506).

Assessment sessions were always conducted before the child's regularly scheduled lunchtime. A session consisted of six consecutive presentations of each of the four different food items, for a total of 24 trials per session. One food item was selected from each category and items were cut into bite size pieces, except the one food type per session that was presented in a puréed form (Ahearn et al., 2001, pp. 506-507).

For the analysis of the data, a low level of acceptance within a food group was defined as ten or fewer bites accepted. Moderate acceptance was defined as eleven to twenty bites accepted within a group, and acceptance of 21 to 30 bites within a food group was considered high (Ahearn et al., 2001, p. 508).

The results from this study indicated that seventeen of the thirty participants exhibited selectivity for food type or texture. Eight of those children demonstrated overly selective acceptance, three were moderately selective, five were mildly selective, and one exhibited selectivity only for texture. No participants exhibited selective acceptance of vegetables. The investigation suggested that more than half of the participants exhibited low overall levels of food acceptance. These results confirm the hypothesis that children with autism are more likely to exhibit a feeding disorder, which previous survey studies have suggested (Ahearn et al., 2001, pp. 508-510).

Intervention

Identifying and addressing feeding problems

Kimberly Kroeger-Geoppinger, an assistant pediatrics professor at the Cincinnati Children's Hospital Medical Center, developed strategies that will help parents identify their child's eating habits. She created steps parents and clinicians can take in "overcoming feeding problems in children with autism" (Rudy, 2010, p. 1).

The first step is designed for parents to recognize when their child is beginning to reject foods that were previously accepted. If the problem is not properly identified, it is possible that the child will self-select food items down to just a few foods, served in only one way, and accepted at only one particular location. Next, parents are instructed to select foods that have a similar flavor, appearance, and texture to the ones their child is already eating. It is important to take small steps in introducing new foods. "A first step to introducing a new food might be simply placing the food on your child's plate. If even that leads to problems, you can start by placing the food on the child's plate for only a few seconds" (Rudy, 2010, p. 4).

Kroeger stated it is important to reward the child for each successful step. After a new food on the plate is tolerated by the child, take more baby steps. Subsequent steps would include:

touching the food, smelling the food, bringing the food to the lips, touching the food with the tongue, tasting the food, and then finally having the child taste the food every day for two weeks. "If the child continues to reject the food after tasting it every day for two weeks, it's probably time to decide that this is just not going to be a preferred item" (Rudy, 2010, p. 5).

Finally, Kroger explained that it is essential for parents and clinicians to stay calm and to not create a power struggle when introducing new foods (Rudy, 2010, p. 6). Kroger noted that it is easy for parents to get frustrated with a child who simply won't eat anything new. Therefore, these situations should be avoided. The best way to do this is to "set the bar low enough that the child will almost always succeed" (Rudy, 2010, p. 6).

Medical, sensory, and behavioral factors

Twachtman-Reilly, Amaral, and Zebrowski (2008) tried to identify important components of the assessment and treatment of feeding disorders in the autism spectrum population and outline specific therapy techniques designed to improve assessment and treatment within school settings. They found that children with autism demonstrated both physiological and behavioral factors in their feeding problems (pp. 261-262).

Twachtman-Reilly et al. (2008) stated that sensory processing issues and gastrointestinal issues are the two main

types of physiological issues that can directly or indirectly impact feeding. Behaviorally-based factors that may interfere with the child's feeding experience would include: repetitive and ritualistic behaviors, executive functioning difficulty (problems with planning and mental flexibility), fear and anxiety, and problems with social language skills. To address these problems it is important for the speech-language pathologist to enhance predictability in order to reduce anxiety and define task expectations by possibly providing a visual schedule. The school SLP may need to work with family members and special educators to create and establish more functional mealtime rules and routines. Direct assessment of food selectivity, expressive and receptive language skills, and sensory-based factors are crucial for children on the autism spectrum in order to successfully design a feeding program (pp. 262-267).

Twachtman-Reilly et al. (2008) stated that intervention must be designed based on the specific types of feeding difficulty experienced by the child with autism spectrum disorder and should be addressed through team collaboration. "Sensory based strategies may be needed to address behavioral responses such as decreasing self-stimulatory behavior, improving attention, and regulating the activity level needed

for in-seat behavior that may interfere with the child's ability to engage effectively in mealtime" (p. 268).

Some other sensory-based treatment techniques would include: facilitation of oral desensitization, oral exercises before mealtime, introduce child-friendly foods, choose smaller portions, combine new foods with familiar foods, and select foods that are similar in flavor, appearance, and/or texture to preferred foods (Twachtman-Reilly et al., 2008 p. 269). Peer modeling may also aid progress by providing a comfortable and relaxed setting for eating (Twachtman-Reilly et al., 2008, p. 269). The authors described the importance of considering sensory-based environmental factors that may interfere with eating behaviors such as noises, smells, lighting, activity level, and movement within the environment (Twachtman-Reilly et al., 2008, p. 269).

Some behaviorally-based treatment techniques mentioned in by Twachtman-Reilly et al. (2008) include: methods of food presentation, liquid fading, use of reinforcers, backward chaining, and the use of prompting. The authors recommended providing external rewards for appropriate eating. This may be an effective motivator for the child with autism to participate in feeding therapy. Twachtman-Reilly and colleagues (2008) mentioned that generalization to the least restrictive

environment possible for safe and effective feeding should be an important component of the child's feeding plan (p. 269).

To further support the effectiveness of behaviorally-based intervention techniques Sharp, Jaquess, Morton, and Herzinger (2010) conducted a systematic review of literature regarding treatment of pediatric feeding disorders. Forty-eight single-case research studies that evaluated treatment of severe food refusal or selectivity were reviewed. All of the studies included behavioral interventions, such as methods of food presentation and the use of reinforcers. The results of the literature review suggested that behavioral interventions are associated with significant improvements in feeding behavior (p. 348).

Conclusion

This research paper has given me a deeper and more comprehensive understanding of feeding problems and other developmental issues that coincide with autism spectrum disorders. However, as a result, this newly acquired knowledge prompted me to raise further questions on the topic of autism and feeding disorders.

While researching, I could not find many studies that focused on feeding intervention specific to autism. The majority of the articles simply compared the feeding behaviors of children with autism to typically developing children.

Twachtman-Reilly et al.(2008), offered speech-language pathologists some intervention options for treating children with autism that have behavioral and psychological issues related to feeding disorders, and Sharp et al.(2010) confirmed the effectiveness of behavioral interventions, but what happens if a child does not respond to these techniques? What would be the hierarchy of intervention?

Therefore, I ask myself, is it possible for a child with autism, who has a severe feeding disorder, to obtain typical feeding function? And, if a child is noncompliant in feeding therapy then what does the future hold that individual? These questions and many more should be further addressed in future research. By answering these questions, it would allow clinicians to account for the effectiveness of their services when reporting to clients, families, and insurance companies.

I believe that it is important to understand this complex disorder and to effectively collaborate with other professionals for proper assessment and intervention of feeding disorders specific to autism. As a future speech-language pathologist, I will use the knowledge derived from this project to make informed clinical judgments when treating the autism spectrum population. It is my hope that the information from this research paper will help guide other clinicians in their professional decision making as well.

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