

Treatment Outcomes for Severe Feeding Problems in Children With Autism Spectrum Disorder

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There is abundant research to support that children with autism spectrum disorder (ASD) exhibit challenging feeding behaviors. Despite increase in empirical evidence supporting the role of behavior analysis in treating severe feeding problems, evaluation of the short- and long-term effects of these treatments for a large group of children with ASD is warranted. The purpose of the current study was to evaluate treatment outcomes of an interdisciplinary feeding program for 46 children with ASD. A retrospective chart analysis indicated these children were treated successfully overall and follow-up data suggest gains were maintained following discharge from the program.

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Feeding problems are quite common in children, affecting those with developmental disabilities and medical conditions as well as children who are typically developing. Estimates vary but it has been reported that

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between 20% and 40% of all children exhibit some form of feeding problem. For individuals with developmental disabilities, prevalence of feeding problems is even higher (Burklow, Phelps, Schultz, McConnell, & Rudolph, 1998; Field, Garland, & Williams, 2003; Linscheid, Budd, & Rasnake, 1995). The term *feeding problems* typically refers to some pattern of oral or enteral consumption of nutrients that deviates from the norm enough to lead to negative social or health consequences. Feeding problems vary by etiology, behavioral topography, and severity; thus, there are different methods to determine when children's feeding or eating behavior(s) have become a "problem" (Kedesdy & Budd, 1998).

One method used to differentiate among the broad range of feeding problems is to evaluate the danger associated with the mealtime behavior. Mild feeding problems are usually temporary, resolve without significant intervention, and are typically managed by pediatricians (Finney, 1986). However, severe feeding problems associated with an inadequate amount of nutrients consumed and extensive weight loss can be life-threatening and do not often cede without intense intervention. Even cases that require intense intervention but are not life-threatening can put children at risk for illness and prohibit them from gaining the benefit of positive interpersonal interactions (Babbitt, Hoch, & Coe, 1994).

The assortment of behaviors that constitutes a feeding problem also varies from child to child and include food refusal (e.g., crying, head turning, spitting out food, throwing utensils, packing or holding food in mouth, aggression, and getting out of the seat), coughing/gagging, and vomiting. For example, some children may passively (i.e., keeping lips closed) refuse all food, while others may exhibit disruptive or self-injurious behaviors during mealtime.

The causes or maintaining factors of many feeding problems include medical conditions (e.g., gastroesophageal reflux [GER]), physiological dysfunctions due to anatomical abnormalities (e.g., cleft-lip and palate), oral-motor delay or dysfunction (e.g., cerebral palsy, dysphagia), and reinforcement of inappropriate behavior during feeding (Iwata, Riordan, Wohl, & Finney, 1982; Linscheid et al., 1995; Manikam & Perman, 2000). In most cases, multiple factors contribute to and maintain the feeding problem and the variables associated with the onset and persistence of feeding problems vary between children.

Feeding Problems and Autism Spectrum Disorder

Reports from parents, teachers, and behavioral health practitioners suggesting that a significant number of children with autism spectrum disorder

(ASD) exhibit problematic and challenging feeding behaviors have been supported by recent research (Ahearn, Castine, Nault, & Green, 2001; Ledford & Gast, 2006; Schreck, Williams, & Smith, 2004). In these studies, children with ASD have significantly more feeding problems than children without. Moreover, “food selectivity” (eating a narrow variety of food) was a commonly reported problem in this population (Ahearn et al., 2001; Field et al., 2003; Schreck & Williams, 2006). However, it should also be noted that most of these cases of selectivity did not appear severe enough to result in malnutrition or to require intense intervention.

Reasons for the prevalence of feeding problems in children with ASD include a concentration on detail, perseveration, impulsivity, avoidance of novel situations/stimuli, sensory defensiveness/impairments, social skill deficits, and food intolerance (Cumine, Leach, & Stevenson, 2000; Ledford & Gast, 2006). Interestingly, Schreck and Williams (2006) did not find evidence in support of the commonly held assumptions that feeding selectivity of children with autism could be related to their autism symptoms, such as problems in changing routines or sensory difficulties with textures. They did find that children with autism were idiosyncratically selective in the types of food that they accepted, but not that there was a relationship between severity of autistic characteristics and food selectivity. In addition, Williams, Gibbons, and Schreck (2005) found that the diets of selective eaters who were typically developing were similar to diets of selective eaters with ASD or other types of special needs.

Successful treatment of feeding problems requires identification and management of any ongoing medical problems contributing to the feeding difficulty (Eicher, 1977). Some research suggests that children with autism frequently present with gastrointestinal (GI) difficulties (e.g., constipation, vomiting, food allergies) (Valicenti-McDermott et al., 2006). It would appear that the presence of GI discomfort would be one possible cause of a severe feeding problem, but Kerwin, Eicher, and Gelsing (2005) found no clear relationship between GI discomfort and the onset of severe feeding problems in a sample of children with PDD. Moreover, other reviews have found no differences in the prevalence of symptoms of GI disorders between children with autism and typically developing children (Erickson et al., 2005; Levy et al., 2007), supporting the notion that autism itself does not predispose a child to increased GI abnormalities. While it remains clear that children with ASD tend to have a higher prevalence of food selectivity (although not always severe enough to require intense intervention) than a typically developing child, there is no widespread explanation for this phenomenon, medical or otherwise.

Treatment for Feeding Disorders

Numerous studies have demonstrated the effectiveness of behavioral interventions in treating pediatric feeding problems. Often used in conjunction with an interdisciplinary team, effective behavioral treatments include differential reinforcement, escape extinction, the Premack principle, and textural manipulation (Greer, Gulotta, Masler, & Laud, 2008; Kerwin, 1999; Linscheid, 2006). As a rule, the least restrictive, effective intervention should always be used for severe problem behavior (Van Houten & Rolider, 1988). Increasing food acceptance by simply using positive reinforcement-based interventions (e.g., Riordan, Iwata, Wohl, & Finney, 1980; Thompson, Palmer, & Linscheid, 1977) would be ideal. However, given the substantial consequences of prolonged food refusal, it is sometimes necessary to use a more intrusive procedure when positive reinforcement is ineffective. Physical guidance (Ahearn, Kerwin, Eicher, Shantz, & Swearingin, 1996; Kerwin, Ahearn, Eicher, & Burd, 1995; Riordan, Iwata, Finney, Wohl, & Stanley, 1984) and nonremoval of the spoon (Ahearn et al., 1996; Babbitt et al., 1994; Kerwin et al., 1995) combined with positive reinforcement are intensive intervention packages that have been shown to effectively produce food acceptance (Piazza, Patel, Gulotta, Sevin, & Layer, 2003).

While there have been single case studies demonstrating efficacy of behavioral interventions for feeding problems in children with ASD (Freeman & Piazza, 1998; Wilder, Norman, & Atwell, 2005), the majority of the empirical evidence is based on children with medical conditions related to feeding. Although findings from these studies focusing on other populations are promising, effective interventions in other populations may not generalize to a group of children with ASD due to their unique cognitive and behavioral profiles.

In a review of feeding literature in children with ASD, Ledford and Gast (2006) obtained information as to treatment of maladaptive feeding behaviors by conducting electronic and ancestral searches of peer reviewed journals between 1994 and 2004. Nine intervention studies met inclusion criteria, and all utilized behavioral techniques. While consumption of previously refused foods increased in all nine studies, limitations cited by the authors included a lack of directly observable measures of treatment efficacy, small sample sizes, and scarcity of follow-up data. Therefore, a study evaluating directly observable treatment outcomes for feeding problems in a large group of children with ASD is warranted. With further addition of

follow-up data, the speculation regarding whether the gains made in an intensive program can be maintained despite the challenges faced by caregivers of children with ASD may be addressed.

The goal of our study was to empirically expand on the information provided in previous cases studies and clinical reports by measuring the treatment outcome of 46 children with ASD admitted to an intensive interdisciplinary feeding program. Data on treatment outcome, caregiver's perception of their child's feeding problems, caregiver satisfaction at discharge, and follow-up were collected for each participant. We hypothesized that there would be a significant improvement in feeding behaviors from admission to discharge. We also hypothesized that the caregiver's perception of the frequency of their child's feeding problems would significantly improve from admission to discharge. In addition, we expected that gains made in the program would be maintained at follow-up.

Methods

Participants

Demographic Variables

The sample included 46 children between the ages of 36 and 145 months (mean age of entry = 69 months) with a diagnosis of ASD at the time of admission. There were 40 males and 6 females included. While the majority of the sample consisted of Caucasians ($n = 24$), there was also a variety of different ethnicities represented including 5 African Americans, 3 Asians, 3 Latinos, 1 American Indian, and 10 others/unknowns. Average length of treatment from admission to discharge was 47 days, with 23 participants enrolled in the inpatient program and 23 in the day treatment program. Inpatients received behavior therapy 3 hours a day and oral motor therapy 1 hour a day, 7 days a week. Intensive day treatment individuals received behavior therapy 3 hours a day and oral motor therapy 1 hour a day, 5 days a week. Behavior therapy consisted of systematic meal sessions with individualized behavior protocols involving antecedent and consequence manipulations in the meals. Oral motor therapy conducted by a speech and/or occupational therapist was used to determine a child's skill and safety in eating by performing nutritive and non-nutritive oral motor exercises. Other members of the team included a gastroenterologist, pediatrician, nurse practitioner, and nutritionist whose focus was to assure that each participant was medically and nutritionally stable during the admission. Finally, a social worker provided emotional support for the caregivers

Table 1
Presence of Medical Diagnoses/Issues^a

Medical diagnoses/issues	Number	(%)
Failure to thrive	7	15.2
GER	26	56.6
Prematurity (less than 32 weeks)	6	13.0
32-38 weeks	9	19.6
Food allergies	8	17.4
Nissen fundoplication	7	15.2
Esophagitis/gastritis/duodenitis	11	23.9
Chronic lung disease	6	13.0
Cerebral palsy	5	10.9
TEF	0	0.00
Tracheostomy	0	0.00
Cleft palate	0	0.00

GER = Gastroesophageal reflux; TEF = tracheo esophageal fistula.

a. $N = 46$.

throughout the admission; more detailed descriptions of the programs can be referenced in Greer et al. (2008) article.

Medical Diagnoses/Issues

A minority of participants exhibited medical diagnoses and issues in addition to their ASD diagnosis (see Table 1), with the most prevalent diagnosis being GER.

Dependent Variables

Participant Feeding Behaviors

Percent occurrence of directly observable feeding behavior for each child was averaged across the first five sessions of the initial treatment phase (at admission) and the last five sessions of the final treatment phase (at discharge). Length of these phases varied depending on clinical necessity, lasting long enough to identify stable patterns of behavior. Percent change of these variables was calculated by taking the mean value of the target variable at admission minus the mean value of the target variable at discharge.

Acceptance. *Bite acceptance* was defined as when the child opened his/her mouth and the entire bite was deposited within 5 seconds of the initial presentation.

Refusal behaviors. *Refusal behaviors* were defined as each time the child turned his or her head (and/or body) 45° past midline during the presentation of the bite. Disruptions were scored every time any part of the child's body came into contact with a feeding utensil or the therapist's hand/arm while the bite was presented. During self feeding sessions, inappropriate refusal behaviors were scored when a child moved the spoon to a position more than 45° from midline.

Negative vocalizations. A *negative vocalization* was defined as when the child exhibited crying, screaming, or making negative/refusal statements.

Grams consumed. *Oral intake* was defined as the number of grams of food consumed at each meal.

Caregiver Assessment Measures

Children's Eating Behavior Inventory (CEBI). The CEBI is a 40-item caregiver report measure intended to assess eating and mealtime problems across a wide variety of children with medical and developmental disorders (Archer, Rosenbaum, & Streiner, 1991). Two scores are derived from this measure: (a) the Total Eating Problems score which measures the frequency of 19 different eating behaviors through the use of a 5-point rating scale, and (b) the Total Perceived Problems score which asks caregivers to evaluate whether or not each behavior presents a problem for the family. Test-retest reliability has been reported at .87 for the Total Eating Problem score and .84 for the percentage of items perceived to be a problem (Archer et al., 1991). This measure has been used previously for children with autism (Archer & Szatmari, 1991).

Caregiver satisfaction scores. Caregiver satisfaction scores were obtained for each child via a structured questionnaire that was completed by the child's primary caregiver at discharge. Overall satisfaction score (on a Likert-type scale from 1 to 5) was based on questions related to effectiveness of the behavioral approach for their child's feeding disorder, as well as the competency of the behavior psychology staff throughout admission.

Follow-up. Multiple attempts were made over a 2-3 month period to contact each child's caregivers for follow-up information regarding volume, variety, texture, mealtime refusal behaviors and caregiver satisfaction via a structured questionnaire. A total of 63% of the sample completed the

follow-up questionnaire. The average time between the date of discharge and collection of the follow-up data was 40 months (more than 3 years).

Procedure

Data were collected by trained therapists in accordance with accepted procedures to secure patient confidentiality throughout each child's admission. Informed consent was obtained from the caregivers as part of a routine procedure upon admission into the program.

Case records of an intensive interdisciplinary feeding program were systematically reviewed for the period between December 2000 and February 2008. Children of at least 3 years of age with an autism diagnosis upon admission were included in the study. Children were excluded if they were discharged early due to (a) a medical reason decided upon by the treatment team in which continuing treatment was unsafe or unreasonable, and/or (b) a personal reason decided upon by the child's primary caregivers in which continuing treatment was not acceptable. Overall, 46 individuals were chosen for participation in this study. Directly observable outcome measures were obtained throughout each child's admission. Scores were also collected from the CEBI and a caregiver satisfaction survey, which were given to the primary caregiver for completion.

Reliability of Data Collection

Inter-observer Agreement

Inter-observer agreement (IOA) on directly observable child feeding behaviors was calculated for at least 30% of the sessions for each child (randomly selected). An average of 149 sessions was run for each child. Data were collected by independent observers either in vivo or with both observers viewing videotaped sessions simultaneously. All observers received training and demonstrated competency on the scoring procedures before collecting data. Total agreement was averaged for each child across each feeding behavior by dividing the number of agreements by the number of agreements plus disagreements and multiplying by 100%. Average inter-observer agreement for the sample was 96.33%, ranging from 88.63% to 99.76%.

Inter-Rater Reliability

Inter-rater reliability of the chart reviews for 10% of the sample (randomly selected) was collected. The case records of these children were systematically reviewed by two data collectors. Reliability of data collection was then

Table 2
Analyses of Variance for Participant Feeding Behaviors^a

	Admission	Discharge	<i>F</i>	<i>p</i> -Value
Mean [95% CI] acceptance (%)	15.56	91.42	119.69	<i>p</i> < .000*
Mean [95% CI] refusal behaviors (rates per trial)	25.00	21	8.18	<i>p</i> < .007*
Mean [95% CI] neg. vocalizations (%)	19.93	4.45	15.65	<i>p</i> < .000*
Mean [95% CI] grams consumed	24.41	247.82	151.31	<i>p</i> < .000*

a. *N* = 46.

**p* < .05.

evaluated across each variable by dividing number of agreements by the number of agreements plus disagreements and multiplying by 100%. Interrater reliability was found to be 92.97%, ranging from 82.42% to 100%.

Results

Criteria for program evaluation were analyzed and the results are described below. All analyses were computed using the Statistical Package for the Social Sciences (SPSS; 2008).

Participant Feeding Behaviors

In order to identify differences in the occurrence of feeding behaviors from admission to discharge, a repeated measures ANOVA was used. Significant differences were found in percentages of acceptance $F(1, 42) = 119.69, p < .000$, refusal behaviors $F(1, 42) = 8.18, p < .007$, negative vocalizations $F(1, 42) = 15.65, p < .000$, and grams consumed $F(1, 42) = 151.31, p < .000$ from admission to discharge. Specifically, acceptance, refusal behaviors, and grams consumed increased significantly while negative vocalizations significantly decreased from admission to discharge (see Table 2).

Caregiver Assessment Measures

CEBI. A paired samples *t*-test was used to identify differences among the Total Eating Problems score (on the CEBI) at admission and discharge.

Table 3
T-test for Caregiver Assessment Measure and Caregiver Satisfaction

	Admission	Discharge	<i>t</i>	<i>p</i> -Value
Mean [95% CI] CEBI total eating problems score	107.12	99.62	3.07	<i>p</i> < .004*
Mean [95% CI] caregiver satisfaction ^b	n/a	4.48		

CEBI = Children's Eating Behavior Inventory.

a. *N* = 46.

b. Likert-type Scale 1-5 (1 = *unsatisfied* and 5 = *extremely satisfied*).

**p* < .05

A significant decrease in the Total Eating Problem score from admission to discharge was found, $t(1, 40) = 3.07, p < .004$.

Caregiver satisfaction scores. An average of the total caregiver satisfaction scores at discharge was noted. Results showed that average caregiver satisfaction ranked between *very satisfied* and *extremely satisfied* (see Table 3).

Follow-Up. The outcome variables that were evaluated at follow-up were: variety of foods consumed, texture advancement, protocol usage, the frequency of mealtime refusal behaviors, and whether or not the caregiver would recommend the program to someone else. More specific follow-up results are described in Table 4.

Discussion

It has long been established that children with ASD exhibit a variety of feeding and meal-time problems (Ahearn et al., 2001; Archer & Szatmari, 1991; DeMyer, Ward, & Lintzenich, 1968; Kanner, 1943; Minshew & Payton, 1988). These findings have been corroborated by Schreck et al. (2004) who found that parents of children with autism report significantly more texture and food selectivity, as well as brand and utensil specific consumption. As abundant as feeding problems are in children with ASD, effective interventions that work well in other populations may not generalize to a large group of children with ASD due to their unique cognitive and behavioral profiles. The purpose of the present study was to evaluate

Table 4
Outcome Variables at Follow-Up^a

	1-3 Years From Discharge (<i>n</i> = 14) % (Frequency)	3+ Years From Discharge (<i>n</i> = 15) % (Frequency)
Variety of foods from discharge to follow-up		
Greater variety	78.57 (11)	53.33 (8)
Less variety	0.00 (0)	20.00 (3)
Same variety	7.14 (1)	0.00 (0)
Texture of foods from discharge to follow-up		
Higher texture	28.57 (4)	60.00 (9)
Lower texture	7.14 (1)	6.67 (1)
Same texture	50.00 (7)	26.67 (4)
Protocol usage at follow-up		
Using protocol	50.00 (7)	33.33 (5)
Not using protocol	28.57 (4)	40.00 (6)
Using modified protocol	21.43 (3)	20.00 (3)
Refusal behaviors from discharge to follow-up		
Has improved	71.43 (10)	100.00 (15)
Gotten worse	7.14 (1)	0.00 (0)
Stayed the same	0.00 (0)	0.00 (0)
Would you recommend program?		
Yes	85.71 (12)	100.00 (15)
No	0.00 (0)	0.00 (0)
Depends	14.29 (2)	0.00 (0)

a. *N* = 29.

whether an intensive interdisciplinary feeding program would be efficacious for a large group of children with an ASD diagnosis and whether the children would continue to thrive following discharge from the program.

Participant Feeding Behaviors

The first hypothesis in the present study was that there would be a significant improvement in feeding behaviors from admission to discharge. This hypothesis was substantiated for all feeding behaviors observed providing support for previous studies that found positive child outcomes for interdisciplinary feeding programs (i.e., Benoit, Wang, & Zlotkin, 2000; Byers et al., 2003; Greer et al., 2008; Irwin, Clawson, Monasterio, Williams, & Meade, 2003; Williams, Riegel, Gibbons, & Field, 2007).

These results are not surprising given that a child admitted to an interdisciplinary feeding program receives a comprehensive approach to what is typically a multifaceted disorder. With the combined support from various disciplines such as occupational therapy, speech and language therapy, and behavioral psychology, a child learns to model appropriate mealtime behavior while building the skills necessary to advance their feeding development. Children with ASD in particular benefit from the rule governed nature of the program, which relies on the structure and consistent application of behavioral principles in treatment. A growing body of empirical evidence exists supporting the use of applied behavior analysis to reduce inappropriate behavior in children with ASD (Ahearn, Clark, MacDonald, & Chung, 2007; Hagopian, Bruzek, Bowman, & Jennett, 2007; Reeve, Reeve, Townsend, & Poulson, 2007), lending credence to this approach.

Caregiver Assessment Measures

Although direct observation of success is important when measuring efficacy of a program, caregiver's perception of success is equally as important. Overall caregiver satisfaction reflects the interdisciplinary team's ability to help his or her child by explaining treatment procedures effectively, training caregivers successfully, and remaining accessible throughout a child's admission. Average caregiver satisfaction at discharge ranked between *very satisfied* and *extremely satisfied* suggesting that caregivers of children with ASD were pleased with their child's results in the program. The second hypothesis was that the caregiver's perception of the frequency of their child's feeding problems would improve from admission to discharge. This hypothesis was confirmed as CEBI Total Eating Problem scores for caregivers decreased significantly from admission to discharge. Greer and colleagues (2008) found evidence to suggest that the Total Eating Problem score of the CEBI serves as a predictor for overall caregiver stress. With the additional aide of interdisciplinary supports such as that of a social worker, a caregiver's overall stress may be positively impacted.

Follow-Up

Follow-up results are pivotal when measuring program efficacy, while it can be argued that the true success of any conventional treatment is the maintenance of gains over time. The third hypothesis was that the gains made in the program for children with ASD would be maintained from the point of discharge to follow-up. Although only 63% of the sample was able to be contacted, a large majority of caregivers (see Table 4) reported that

their children had improved across various domains related to feeding. More specifically, the majority of the sample reported their children eating a greater variety of foods while engaging in less refusal. In addition, a vast majority of caregivers stated they would recommend the program, with only two suggesting that the program was not suited for all children. Less than half of our caregivers stated that they are using the protocol more than 3 years after discharge from the program, with 40% of those stating that they no longer needed to use it. This may be of significant importance to caregivers of children with ASD, as these children often require considerable support as they grow older. The stress for caregivers to meet these challenges may lead one to believe that maintaining gains made in the program to be difficult. However, results in this study show that not only do most of these children do well at follow-up, but the majority is able to maintain gains without implementing as much structure as was required during the program.

Limitations and Future Directions

The present study has clearly demonstrated the effectiveness of an intensive interdisciplinary program in the treatment of feeding disorders in children with ASD. However, the findings in the present study should be viewed in the context of a few methodological limitations.

First, it should be noted that the sample of children who participated in this study are not representative of most children with ASD. On the contrary, the children who are often admitted to an intensive interdisciplinary feeding disorders program are children who have medical issues and/or severe behavioral concerns that require systematic assessment, daily monitoring, consistent structure, intensive caregiver training, and thorough follow-up care. Efficacy of various treatment modalities in a less intensive outpatient setting for children with ASD should be evaluated. Moreover, it remains to be seen whether the efficacy of certain types of treatment is a function of the degree to which a child suffers from ASD.

Another limitation of the present study is that follow-up data were assessed at only one point in time for each participant. Multiple follow-up data points would provide more comprehensive evidence regarding gains after discharge. Additionally, social desirability bias may have played a role in the follow-up results. Although an attempt was made to collect directly observable follow-up data that would eliminate the potential for bias that may come with asking caregivers for their input, it was found that few caregivers returned in person for meal observations. Future studies should focus on

improving means of collecting directly observable follow-up data (i.e., video).

Despite these limitations, this study marks an important contribution to the literature in that the efficacy of an intensive interdisciplinary feeding program across children with ASD was confirmed. While it is still unclear as to what role a diagnosis of ASD plays in the etiology of a feeding disorder, it remains evident that this diagnosis alone should not dissuade the pursuit of appropriate treatment. On the contrary, each child should be assessed as an individual and issues such as his/her feeding history, oral motor skills, and medical status should play a larger role in their evaluation for treatment. The utility in this finding is paramount; caregivers and clinicians should be aware that while a child with ASD may pose difficult challenges in the area of feeding problems, an intensive interdisciplinary program can improve and maintain his/her positive mealtime behavior.

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