

A Multidisciplinary Approach to the Treatment of Comorbid Neurodevelopmental and Medical Problems

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Case Presentation

Jack is a 10-year-old boy with a history of lye ingestion at 18 months, which resulted in esophageal stenosis, vocal cord paresis and dysphagia, aspiration syndrome, and jejunostomy tube (J-tube) placement. He had regular swallow studies over the years subsequent to his ingestion, and started feeding therapy with a speech and language therapist at age 10 while J-tube dependent. Jack had attended outpatient psychotherapy for anger and behavioral concerns for the year prior to presenting for current treatment. A pediatrician had prescribed a stimulant medication for symptoms of attention deficit hyperactivity disorder (ADHD) since age 5. One year before the time of evaluation, the pediatrician had discontinued methylphenidate due to weight loss, which became a primary health concern as his low BMI placed him in failure to thrive range (BMI < 1st%ile). In addition to his medical risk, Jack demonstrated significant impairments across physical, social, psychological, and school functioning, which prompted a referral to the Medical Day Treatment (MDT) program by his pediatrician. The MDT program is a partnership between a children's hospital and school district to provide classrooms utilizing the district's curriculum within a treatment setting housed in the behavioral health section of a children's hospital. The program's services include a nursing team to provide medical supervision and daily medical care, teaching staff from the school district, and a mental health team including psychotherapists (licensed clinical social worker, clinical psychologist, and postdoctoral psychology fellow), milieu support staff, and a consulting psychiatrist.

At the time of enrollment, Jack was not completing

his J-tube feeds at home because it was difficult for his mother to manage his refusal behaviors, which were associated with fears that his J-tube would disconnect in the middle of the night, since that occurred in the past. Jack had completed fourth grade and had an individualized education program (IEP), which included speech therapy, occupational therapy, reading services, and psychological support. Jack presented to the intake with the prior diagnosis of ADHD (noted above), as well as symptoms of depression (sadness, irritability, frequent crying) and anxiety (fears, worries, separation anxiety). His mother stated Jack also exhibited frequent anger, irritability, and school refusal behaviors (eg, crying every morning). She described him as having long-standing difficulties with peers, including no identified friends and experiencing increased teasing over the prior year. Jack lived with his mother and 3 siblings (16-year-old sister and 12-year-old twin sisters, one of whom was severely disabled). Jack's 12-year-old sister had severe physical impairments due to cerebral palsy, which required constant care by his mother. His mother was unemployed and had no outside support from her family. Jack's mother also reported her own history of learning disabilities and mental health problems.

During the initial evaluation, Jack, who was holding a stuffed animal, appeared highly anxious and did not verbally respond to the interviewer. When he did verbally respond, his answers did not match the question or content of the interview and he expressed worries he would continue to be teased at MDT. His responses to the Revised Child Anxiety and Depression Scale (RCADS)^{1,2} suggested clinically-significant levels of separation anxiety, generalized

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anxiety, panic, social phobia, and depression (refer to Table 1 for results).

Based on the reasons for the initial referral and results of our assessment, treatment goals focused on improving caloric intake, addressing anxiety and depression, improving peer relationships, and decreasing impulsivity in the classroom. The psychotherapist coordinated with the nursing team to address barriers to increasing caloric intake and weight gain. The team developed a system to track progress by implementing weigh-ins twice a week and documenting the percentage of food intake at breakfast and lunch. The team recommended changing the timing of J-tube feeds to the evening with video games to address his fear of overnight feeds, and Jack cooperated with this new schedule. A fixed-ratio reinforcement schedule implemented in the program and at home included rewarding increased food intake in order to build more positive associations with the eating experience.^{3,4} This behavioral approach also targeted Jack's fear of choking through exposure and relaxation training. At home, Jack earned marbles in a jar when he completed his feeds and then exchanged the marbles for a videogame. During this time, the psychotherapist provided education to Jack's mother, the nursing team, mental health counselors, and teachers regarding effective behavior-management techniques, such as contingency management and use of positive reinforcement.⁵ Jack was also taught emotion-regulation skills to decrease tearfulness and tantrums during meal times and feeds. Finally, collaboration with the pediatrician resulted in the utilization of home nursing support in order to facilitate consistent feeds at home and provide greater support to Jack's mother.⁶

Prior to admission to MDT, Jack had been prescribed methylphenidate (patch and liquid formulations) starting around age 5 years old. He had stopped taking the stimulant medication approximately 1 year prior to presenting to MDT, due to concerns by his pediatrician about low appetite and weight loss. However, feeding difficulties did not resolve with discontinuation of the stimulant and he did not gain weight. Jack's first psychiatric evaluation occurred within 1 month of admission to MDT. Weight concerns (BMI<1st%) and a reported inability to swallow pills dictated initial medication choices. Stimulants were not an option and atomoxetine does not come in liquid formulation. Given concerns about both

anxiety and poor food intake, the first psychiatrist recommended low dose dispersible olanzapine 2.5 mg at bedtime and mother provided consent. Although olanzapine is not considered first-line treatment for anxiety and does not have an indication for feeding disorders in children, mother reported that olanzapine was beneficial for anxiety, sleep, and weight. It is possible that improvements in symptoms could have resulted from either his participation in the program or start of medication, or a combination of both.

While there was improvement in Jack's emotion regulation, he continued to demonstrate unusual behaviors such as repeating the same random word in response to all questions and responding to social cues inappropriately (eg, laughing in response to his peers' expressions of sadness). He struggled to develop appropriate peer relationships, exhibited communication difficulties, and continued to demonstrate food refusal behaviors and early satiety, leading to no improvement in his BMI. To evaluate if these concerns could be related to a possible developmental disorder, Jack was referred for an Autism Spectrum Disorder (ASD) evaluation. This evaluation included the administration of the Social Communication Questionnaire, Lifetime (SCQ)⁷; the Social Responsiveness Scale, Second Edition (SRS-2)⁸; and the Autism Diagnostic Observation Schedule, Second Edition, Module 2 (ADOS-2)⁹; as well as a developmental history interview with the mother, and a classroom observation of the patient.

Responses on the SRS-2⁸ indicated perceived severe deficiencies in reciprocal social behavior that resulted in moderate interference in everyday social interactions (Total Score, T-score: 75). Such scores are typical for children with a diagnosis of an ASD of moderate severity. Responses on the SCQ⁷ indicated significant perceived difficulties in social communication that were also consistent with a diagnosis of an ASD. The administration of the ADOS-2 was modified on the basis of his language level and developmental age. Based on the standardized protocol of the ADOS-2, he was administered Module 2 (Phrase Speech) instead of Module 3 (Fluent Speech, Child/Adolescent). He displayed several communicative strengths during the ADOS-2 administration, including the use of communicative gestures (eg, pointing) and response to the examiner's questions. His areas of weakness included difficulty initiating and maintaining a conversation

(ie, conversation occurred only when he was asked a question and did not elaborate), a noticeable lack of eye contact, few social overtures, and communication mostly to request items or assistance from the examiner. No restricted and repetitive behaviors were observed during the ADOS-2 administration, however, hand flapping and repetitive finger movements were noted during the classroom observation.

Jack's overall Total score on the ADOS-2 Module 2 algorithm for children aged 5 years or older was consistent with an ADOS-2 Classification of autism (specific ADOS-2 scores are not reported as per the manualized recommendations of the ADOS-2). His ADOS-2 Comparison Score further indicated that on the ADOS-2, he displayed a moderate level of autism spectrum-related symptoms as compared with those who are classified as having ASD on the ADOS-2 and are of the same chronological age and language level. Based on these findings, cognitive behavioral interventions were modified to address social and communication deficits associated with autism.¹⁰

To address depression and anxiety, Jack participated in role plays about how to effectively express his emotions. He was introduced to step-by-step emotion regulation strategies to use when becoming dysregulated, and visual cues were placed throughout his classroom to remind him to use these strategies. And while Jack showed moderate progress in emotion identification and expression, he struggled with applying his skills learned in therapy to the classroom due to impulsivity and inattention. Given this, a psychiatric evaluation was requested.

Jack was evaluated by the new MDT psychiatrist consultant for ongoing concerns about ADHD symptoms as evidenced by the teacher Vanderbilt¹¹ results (inattention and hyperactivity both 9/9). At the time, Jack continued to take olanzapine dispersible tablets. The psychiatrist discussed treatment options for ADHD with both mother and the pediatrician, who supported the use of either an alpha 2 agonist or a stimulant given that Jack's weight could be closely monitored in the program. The patient was started on guanfacine, which was titrated slowly to 0.5 mg twice a day over a 2-month period (the initial titration was slow because it was unknown if Jack would be consistently able to swallow pills, but he ultimately was able to swallow

the medication without difficulty). Vanderbilt assessments suggested some improvement in ADHD symptoms, though they continued to be in the diagnostic range for ADHD. (Teacher scores-inattention 6/9 and hyperactivity 7/9, and parent scores-inattention 2/9 and hyperactivity 6/9.) Guanfacine was changed to a slow release version guanfacine SR (1 mg) to improve coverage. After the change to guanfacine SR 1 mg, Jack's mother noted a more marked improvement in symptoms, including increased focus and decreased hyperactivity. Jack's psychotherapist also reported benefits, including Jack's improved ability to respond to redirection and increased participation in program activities.

Jack had a break in medication management due to an insurance interruption that impacted access to psychiatric services billed to insurance, but not Jack's enrollment in the MDT program*. During this time, the family was unable to obtain his medications for about 1 month; guanfacine SR and olanzapine were therefore discontinued and Jack's sleep and behaviors worsened. Once insurance was re-instated, mother consented to restarting 1 medication at a time, beginning with guanfacine SR 1 mg daily. Jack's mother reported that Jack's listening abilities improved and he responded well to redirection. Olanzapine was not restarted since anxiety had decreased and there was no clear indication for the medication.

In individual psychotherapy, behavioral strategies such as practicing impulse control and regulating emotional responses were used to support the positive effects of medication. Jack showed an improved response to learning skills, and new behavioral recommendations were made both to the teacher to implement in the classroom, and to his mother to implement in the home.^{12,13} These recommendations focused on the use of praise, simplifying expectations into small steps using visual cues, and reducing distractions.

Although Jack's emotional and behavioral functioning improved with these interventions, he continued to struggle with gaining weight. Jack's psychotherapist reported concerns about Jack's continued weight loss and mother's ability to ensure Jack was consuming sufficient calories at home to the Department of Social Services (DSS). DSS assigned a care coordinator to work in the home and to assist Jack's mother with

*MDT receives funding from the state budget and does not receive direct reimbursement from Medicaid; this allows for MDT services to continue during a temporary disruption in insurance coverage.

navigating the healthcare system. Prior to DSS involvement, Jack's mother communicated with the treatment team about her own mental health challenges, which seemed to interfere with implementing behavioral approaches in the home and limit the patient's weight gain. After DSS became involved, mother began her own mental health treatment. The treatment team continued to work with the DSS coordinator, who regularly attended treatment meetings with the mother. The coordinator served as a bridge between the program and home, and was able to help Jack's mother follow the recommendations made by the team. As a result, Jack's mother was able to implement recommendations made by the team, including behavioral strategies to manage problem behaviors during feeds.

This multidisciplinary team approach to assessment and treatment yielded substantial improvements across areas of Jack's functioning: school, social, emotional, behavioral, and health. The patient presented to the treatment program with concerns related to school refusal, failure to gain weight, social relationships, and emotional and behavioral symptoms. Jack's school refusal behaviors immediately extinguished, with 98% attendance in the treatment program during the school year and over the course of 2 summer programs. His mother reported that he showed no refusal behaviors or separation anxiety, getting ready in the mornings with high cooperation and no need for encouragement. Jack also responded well to a fixed ratio reinforcement schedule implemented to increase medical adherence. His food intake on the unit increased from one-quarter of breakfast and one-half of lunch to one-third of breakfast and three-quarters of his lunch, and he consistently drank his meal supplement twice a day without challenging behaviors. Jack's BMI increased from 13.1 (<1st%) at intake to 14.4 (2nd%) at 15 months; this indicated a weight increase of 11 pounds. Notably, his BMI peaked at 15.2 (12th%) at almost 6 months into treatment and weight fluctuations have been documented over the course of his 15 months of care.

The RCADS^{1,2} and the Peds Quality of Life (PedsQL)¹⁴ were administered at intake and at the end of the school semesters to assess symptoms and monitor treatment outcomes (at 7 and 15 months post intake). The PedsQL Family Impact Module (PedsQL FIM),¹⁵ a validated measure of parent and family functioning,

was not part of the intake assessment battery, but was used at other time points during treatment to assess parent and family functioning. Overall, these results indicated that Jack had a significant decrease in anxiety and depression from the clinical range at intake to the normal range in most domains 7 months later, with improvement sustained at 15 months. Jack's functioning and quality of life also appeared to substantially improve across areas, with 15-65 point increases for self-report, and 9-100 point increases for parent-report (the parent rated her child as a 0 for emotional and school functioning at intake; she rated him at 100 for these same areas 15 months later). Results on the PedsQL substantiate observations of improvements emotionally, socially, and in school. Scores on the Peds QL FIM also indicated improved parent and family functioning across all but 1 area between 7 months and 15 months. Please see Table 1 for further details.

Discussion

Children with feeding difficulties often struggle to maintain a healthy weight. Feeding disorders, including avoidance restrictive food intake disorders, are common in children diagnosed with neurodevelopmental disorders, but they can also develop as a result of environmental or biological factors.¹⁶ The existing literature suggests using psychiatric medications, positive reinforcement, and cognitive behavioral therapy for children who have developed feeding difficulties after a medically-traumatic event. Distraction and exposure techniques are recommended for children with an organic cause to their feeding difficulties.⁴ A comprehensive and effective treatment plan is essential in treating feeding disorders, since chronic feeding difficulties can lead to suboptimal growth, social deficits, nutrient deficiencies, and poor academic progress.⁶ Although the literature provides this guidance for feeding disorders, Jack showed minimal response to these interventions, indicating a more complicated diagnostic presentation. Indeed, Jack demonstrated both organic (dysphagia and aspiration) and behavioral (failure to thrive) aspects to his feeding disorder in the context of other serious medical, psychiatric, and psychosocial challenges, underscoring the need for a multidisciplinary approach to treatment.

Jack's treatment course highlights how valuable a thorough assessment process can be in identifying

factors that were previously not identified or addressed in standard approaches to treating feeding disorders. Jack had participated in multiple interventions and evaluations through school prior to his enrollment at Medical Day Treatment, however, his ASD remained undiagnosed. Information from Jack's ASD evaluation helped shape interventions targeting treatment goals to develop age-appropriate social skills, manage peer relationships, and improve feeding behaviors. Jack's developmental level and cognitive, social, and emotional skills were used to set realistic goals in treatment, and they were modified based on Jack's readiness and ability to learn a new skill or behavior. Jack may not have demonstrated treatment gains if the treatment interventions were not modified based on his diagnoses and developmental level. Providers should consider comprehensive medical and psychological evaluation and re-consider interventions used in sessions if symptoms persist after participation in evidence-based treatments.

Jack's psychiatric comorbidities became a central focus of his multidisciplinary treatment and are worthy of further discussion. ASD is a neurodevelopmental disorder affecting approximately 1% of the population and is often comorbid with feeding problems.¹⁷ Behaviors associated with feeding disorders and ASD, including food refusal and avoidance, can have significant negative impacts on the child's health and the parent-child relationship. These behaviors in children with ASD may be the result of sensory, behavioral, or social impairments and are treated with behavioral interventions.⁶ One of the key behavioral influences of ASD on feeding difficulties may be symptoms of repetitiveness, rituals, and hyper- or hyposensitivity to sensory input aspects of the disorder. Children diagnosed with ASD may have specific rituals associated with meal preparation and meal times. Additionally, children diagnosed with ASD have higher rates of gastrointestinal distress, which may play a role in the development of feeding problems. However, the relationship between feeding, ASD, and medical diagnoses have not been parsed out in the literature. Since this is the case, a multidisciplinary approach to treatment, at a developmentally appropriate level, is critically important.⁶

In addition, ADHD and anxiety are highly comorbid with ASD,¹⁸ adding complexity to psychiatric and behavioral symptom presentation for a child with

feeding difficulties. Children with comorbid ADHD and ASD demonstrate higher rates of problems with inhibition and greater severity of ASD symptoms than children with ASD alone.^{19, 20} The comorbidity of medical and neurodevelopmental conditions requires careful evaluation and coordination across providers to optimize therapeutic interventions. In Jack's case, ADHD treatment had been limited by concerns of weight loss and feeding/swallowing difficulties that initially limited medication choices. Psychostimulants associated with an increased risk of appetite suppression in children with ASD, similar to the rate in typically developing children.²¹ A recent study reported that extended release guanfacine was efficacious for decreasing hyperactivity and impulsivity in children with ASD, suggesting it is a reasonable alternative to stimulants in children with ADHD, ASD, and feeding problems.²² Indeed, this case illustrated negative outcomes of untreated ADHD, including a decline in behavioral functioning that negatively impacted academic and social functioning. The addition of medication to target ADHD symptoms of impulsivity and inattention that did not suppress Jack's appetite allowed the treatment team to implement behavioral and cognitive behavioral strategies to address other medical and psychological symptoms.

Identification of barriers to treatment and implementation of a plan to address barriers to treatment is as important as any therapeutic intervention in complex pediatric cases,¹⁰ and the multidisciplinary team's ability to address the challenges in Jack's home environment were particularly critical for his treatment. While DSS involvement is often resisted by families due to negative misperceptions and feelings of disempowerment, it was critically important to addressing the challenges Jack's mother faced in managing his complex medical and psychiatric problems.²³ Feeding difficulties can be a substantial burden for families, especially in single caregiver homes with multiple children with special health care needs. Providers should become familiar with the organizations and services available to families and use those resources to help bridge the gap between office and home. This case also exemplifies the importance of using a range of methods to evaluate progress and outcomes, including scores from validated measures, observational data, and objective metrics.

Conclusion

Jack's successful treatment involved the use of multiple intervention modalities, the work of a skilled multidisciplinary team, and the development of a system of care. Also critical was the sustained engagement of this team and system over a 15-month period, which was necessary to realize meaningful progress. This collaboration of medical care, psychological treatment, psychiatric consultation, family support, schools, and community resources models the ideal approach to a patient suffering from medical, emotional, academic, social, behavioral, and familial

challenges. Each intervention may have had some success in isolation, but it is likely that their combination resulted in synergistic effects, and greater and more sustained improvements than would have been achievable with a less integrated approach. The Medical Day Treatment model is uniquely capable of the coordinated, multidisciplinary approach to assessment and ongoing treatment that patients like Jack desperately need if they are to move from pervasive functional deficits to thriving across domains of functioning essential to optimal development and positive outcomes.

Table 1. Psychological outcome measure results over time

	Intake		7 Months		15 Months	
	Parent	Self	Parent	Self	Parent	Self
RCADS						
Generalized Anxiety	70	74	51	49	35	45
Panic	51	73	41	50	45	55
Social Anxiety	75	84	43	45	35	47
Separation Anxiety	>80	78	>80	79	65	59
Depression	>80	84	69	66	72	50
PedsQL						
Physical	91	59	100	75	100	75
Emotional	0	40	50	55	100	60
Social	25	35	90	65	100	50
School	0	20	70	70	100	85
Total	37	41.3	80.4	67.4	100	68.5
PedsQL Family Impact						
Physical	N/A		42		75	
Social	N/A		6.25		37.5	
Emotional	N/A		60		100	
Cognitive	N/A		45		10	
Communication	N/A		25		50	
Worry	N/A		55		85	
Total	N/A		36.81		53.47	

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