Eating and Feeding Difficulties in Patients With Intellectual and Developmental Disabilities: Four Cases

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Eating problems in patients with intellectual or developmental disabilities represent unique challenges for the clinician. We present four cases of eating problems in patients with intellectual and developmental disabilities. The cases illustrate the complexity of these eating problems when associated with cognitive and/or developmental disabilities.

Keywords: developmental disability, eating disorders, intellectual disability, mental retardation, pica, Prader-Willi syndrome, psychiatric disorder, rumination

Recently, more attention has been given to the co-occurrence of psychiatric illness and developmental/intellectual disabilities. The impact of subnormal intelligence on the prevalence, form and course of psychiatric symptoms can be significant. Cognitive problems that are acquired, genetic or idiopathic may contribute to the etiology of the psychiatric illness, affect the presentation of symptoms and influence the response of the illness to treatment. Similarly, developmental disabilities such as autism, both high and low functioning, may be associated with a variety of psychiatric conditions. Nylander and Gillberg report that 3.2% of patients attending an adult psychiatric clinic had an autism spectrum disorder.

The following cases illustrate examples of patients with eating disorders and feeding problems and intellectual and developmental disabilities. The cases were selected from a series of patients seen in the Eating and Weight Disorders Clinic of the Johns Hopkins Hospital, the Special Needs Clinic of the Johns Hopkins Bayview Medical Center and the University of Iowa Hospital and Clinics. Features of eating disturbances in these populations are described and implications for diagnosis and treatment are discussed.

Case A

Mr. A, a 44-year-old white male with Down syndrome and hypothyroidism, was referred to the inpatient Eating Disorders Service for evaluation and treatment of abnormal eating behavior. Mr. A's family reported that the problems had started five years previously in the setting of dental problems that necessitated several tooth extractions. Over the two years prior to admission, the patient had progressively reduced his intake of almost all solid foods. He would drink milkshakes that he would ritualistically prepare for himself and occasionally eat fruits but only after he had peeled and pureed them himself.

A full medical evaluation suggested malnutrition without evidence of gastrointestinal problems or other medical pathology. An abdominal CT was normal and a head CT showed generalized atrophy.

The treatment team felt that Mr. A’s refusal to eat solid foods represented a learned behavior that had developed as a consequence of his dental problems and extractions five years previously.
conjunction with the hospital dietary department, a behavioral program was developed that included “super-shakes” and also capitalized on food preferences the patient had shown prior to his dental work. The patient began showing interest in eating a greater variety of foods, including solid food, and his caloric intake gradually rose to over 1000 calories per day. Although Mr. A’s communication problems made assessment for an affective disorder difficult, a trial of antidepressant medication was started and continued after discharge from the hospital.

Mr. A’s discharge diagnosis was “Eating Disorder, Not Otherwise Specified.”

Case B

Mr. B was a 17-year-old man who had been diagnosed with Prader-Willi syndrome at age 12 and was admitted to the Eating Disorder Service for evaluation and treatment of temper outbursts and uncontrolled overeating. His weight fluctuated between 200 and 300 pounds at home and his daily caloric intake exceeded 15,000 calories at times. The patient frequently became violent at home if he was refused access to food, on one occasion tearing a locked refrigerator door off its hinges to get to the food inside. The patient had full scale IQ of 78, placing him in the borderline range.

In the hospital, caloric intake was limited to 1000 cal/day and a strict behavioral program was instituted that initially consisted of one-to-one supervision and gradually allowed the patient more autonomy as treatment progressed. A reward system was developed that rewarded appropriate eating behaviors with praise and interpersonal interactions. The social worker met regularly with Mr. B’s family to instruct them on the aspects of the treatment plan that were to be continued on an outpatient basis.

Although there were several temper outbursts, the patient increasingly adhered to the strict behavioral contract. He was noted to be “pleasant and cooperative” during the latter part of his hospitalization.

Mr. B’s discharge diagnoses included “Eating Disorder, Not Otherwise Specified” and “Adjustment Disorder.”

Case C

Mr. C was a 44-year-old white male with moderate mental retardation, microcephaly, and a seizure disorder referred to the Special Needs Clinic at Johns Hopkins Bayview Medical Center. He was born in Maryland and lived with his family until age 16. He has been with the same care provider for the past 15 years. During the previous year he had been losing functional skills and exhibiting abnormal eating behaviors.

Mr. C had been doing well in the home of his care provider for the previous 15 years. Two years prior to admission, Mr. C had started stealing garbage from neighbors’ trash cans and eating it, and eating large quantities of food at a time, such as eight bagels or five pounds of bananas. He was also noted to eat non-food items and uncooked food such as hard pasta. Mr. C started hoarding food and stealing food from others. The patient was easily angered and displayed irritable and agitated behaviors toward his peers that compromised his attendance at a vocational program. Although a behavior management plan was developed and implemented at home and at his vocational site, the patient eventually refused to attend the vocational program. At the time of admission, Mr. C was in the process of becoming involved with another structured day program.

A neurologist evaluated Mr. C for seizures, and an EEG revealed low to moderate voltage sharp waves that were more prominent in the left anterior temporal region. He was started on gabapentin. Mr. C was also seen by a psychiatrist and initially treated with thioridazine for behavioral problems, which was subsequently changed to quetiapine. Quetiapine was discontinued because of lack of efficacy and a trial of fluoxetine was started to target his compulsive behaviors. On this medication, Mr. C was reported to be more interactive at home and at his new vocational program, and his abnormal eating behavior was less problematic.

Mr. C was given a diagnosis of Pica, Depressive Disorder NOS, and Moderate Mental Retardation.

Case D

Mr. D is a 33-year-old single male with autism who reached a maximum weight of 250 pounds (6 foot tall) at age 20. After teasing and criticism for being fat, he spent the next 10 years undergoing cycles of weight loss of 50 pounds or more and weight restoration. He discovered that vomiting helped to control his weight and during the two years prior to presentation he started to induce vomiting several times a week and sometimes daily. He began to compulsively exercise sometimes up to 10 hours a day and to the point of exhaustion. Cycles of extreme food restriction...
alternated with binge eating. Purging occurred daily to several times per week. He identified hunger and stress as precipitants for binge eating. By means of exercise, food restriction, and purging, Mr. D had been able to maintain his weight at 181 pounds and feared becoming fat if he were to gain beyond this weight. He was preoccupied with rules for eating and showed perfectionism in other areas of daily life.

Mr. D’s eating disorder symptoms came to medical attention and were diagnosed as bulimia nervosa, purging type. He started outpatient treatment that consisted of increased contact with his support worker and a behavioral program that rewarded reduced exercise and purging behaviors with stickers. Despite this, he continued to have periods of self-starvation alternating with binge-purge cycles. He was admitted to an inpatient eating disorders unit where he was enrolled in a multi-modal program of nutritional rehabilitation, interruption of binge-purge behavior and cognitive-behavioral and group therapies. He was prescribed paroxetine 40 mgs/day and cisaipride 10 mgs BID. His caloric intake was gradually increased to 3000 kilocalories per day in order to maintain a stable weight of approximately 188 pounds. Mr. D did not engage in purging behaviors during the hospitalization and although he showed typical autistic symptoms of social shyness and repetitive behaviors, he appeared to have much improved social interaction in the hospital’s structured environment.

After discharge, he had increased support from a community worker and returned for regular clinic visits. His exercise was limited to three two-hour sessions per week, and he was observed during two meals each day. At four months following discharge, Mr. D had continued to do well, showing no purging behaviors and an increased participation in hobbies and attendance at sporting events.

Mr. D’s diagnoses were autistic disorder, bulimia nervosa, purging subtype, and obsessive compulsive traits.

**DISCUSSION**

The phenomenological presentation and other aspects of co-occurring mental illness and intellectual or developmental disorders raise numerous questions about the nature and treatment of various psychiatric conditions in these populations. Eating disorders and feeding difficulties do occur in patients with intellectual and developmental disabilities. The symptoms and overall presentation of eating problems can be influenced by cognitive and developmental problems.

There have been a variety of psychotherapeutic and pharmacological approaches to the treatment of eating disorders. Psychometric testing has focused on the enduring personality traits of patients with these conditions. Cognitive and psychodynamic therapies have utilized the information about personality to produce more effective treatments for patients with disturbed eating patterns. Distinctions of personality pathology and profiles have been used to better segregate the various Axis I eating disorders. The findings of a recent study suggest that personality patterns may indeed affect Axis I symptoms, the patient’s level of functioning and point to the possible etiology of the disorders.16

Less attention has been given to the area of intelligence and the impact of this dimensional (Axis II) characteristic on the cause and treatment of eating disorders. While it is suggested that the eating disorders frequently occur in individuals with average and above average intelligence, as these cases demonstrate, individuals with borderline intelligence or mental retardation can be identified who also have an eating disorder or feeding problem. Others have found that the eating disturbances found in individuals with intellectual or developmental disability may be either typical of Anorexia Nervosa or Bulimia or a variant of these conditions, or can be characterized by specific, developmentally-related eating behaviors or other psychiatric disorders.

Many individuals with low IQ who are given a diagnosis of “Eating Disorder” do not receive the usual subclass diagnoses of anorexia nervosa or bulimia. The DSM-IV criteria for these disorders are well defined.1 The diagnosis of “Eating Disorder, Not Otherwise Specified” frequently given to individuals with low intelligence reflects the diagnostic dilemma often faced by clinicians who find it difficult to identify in these patients the symptom complex needed for the diagnoses of anorexia and bulimia. Functional and pathological speech impairments are often associated with mental retardation or developmental problems. The patient’s inability to clearly relate the nature of his mental experience may obscure the more typical features of the disorders including the fear of fatness and the distorted body image that patients with normal intelligence might describe. Alternatively, many patients with cognitive or
developmental problems display features of disordered eating behaviors that are related to their intellectual disability or to an Axis I disorder such as obsessive compulsive disorder or affective illness.

Eating disorders are significantly less common in males than in females, and previously unreported in a male with autism. Fisman et al. described a case study of anorexia nervosa and autism in a high functioning early adolescent female with autism. They speculated on co-occurrence of childhood onset of these two disorders because of shared obsessive compulsive symptomatology and possible shared dysregulation of the serotonergic neurotransmitter system.

The impairments in social interactions and communication that characterize autism may influence the diagnosis of the eating disorder and limit the effectiveness of various treatment modalities including group therapy. Mr. D did increase his level of social interaction and group participation as his treatment progressed. He met full criteria for autism as well as bulimia nervosa. After initial lack of success with outpatient treatment, he responded well to a multidimensional inpatient program and has maintained his benefits after discharge. He was able to benefit from some aspects of cognitive as well as behavioral therapy and treatment with an SSRI and a prokinetic agent. Whether the co-occurrence of autism and eating disorders represent a shared underlying obsessive compulsive symptomatology remains to be determined. The simpler possibility is that Mr. D developed an eating disorder because of concerns about body weight and shape and sensitivity to criticism, with resultant, self-sustaining attempts at weight loss provoking binge eating followed by purging, over exercising, and restricted fasting because of lack of ability to drive weight lower or to resist binge eating behavior. The pragmatic use of an SSRI in several of these cases suggests that depressive features and/or compulsive features may help sustain these conditions. Wherever appropriate, prokinetic agents to increase gastric motility or H2- blockers to decrease reflux symptomatology can also be useful for comprehensive management.

Other abnormal eating patterns seen in individuals with intellectual impairment such as ritualistic behaviors around meals and repetitive activities that involve food may represent symptoms of obsessive compulsive disorder in this group of patients. The patient can develop a routine around meals such that he/she only eats at particular times and selects foods of a particular shape, color, or texture. The eating behaviors are consistent with other types of ritualistic and perseverative behaviors that are often seen in individuals with autism and brain injury.

The phenomenological nature of the eating disorder can be a consequence of the type and degree of intellectual impairment. Thus the patient with the Prader-Willi syndrome (Case B) showed eating behavior characterized by gluttonous overeating while the patient with Down syndrome (Case A) exhibited restriction and a selective type of eating pattern.

The patient with Down syndrome had not shown any aggressive behaviors prior to the onset of his eating disorder. The type of disturbed eating patterns he displayed were controlled attempts to limit the amount and types of food he ate. This is in contrast to the patient with the Prader-Willi syndrome who showed aggression in his eating as well as his non-eating behaviors. The aggression and dyscontrol that characterized his eating patterns were consistent with the aggression and impulsivity seen in his other behaviors and his interpersonal relationships. Consistent with these observations are studies that have identified more behavior problems in children with Prader-Willi syndrome than in children with Down syndrome.

While little has been written about primary eating disorders in those with MR/DD, there has been more investigation of affective illness in these populations. Some of the same diagnostic concerns and treatment issues pertaining to the intellectually or developmentally disabled individual with an eating disorder also apply to patients with developmental problems or intellectual disability and depression. Affective illness may be masked by the patient’s inability to relate the nature of his mental experiences. The clinician must rely on other cues from the mental status examination and history to arrive at a diagnosis of affective illness. Neurovegetive abnormalities including disturbed eating patterns must always be considered suggestive of affective illness in the patient with intellectual disability or a developmental disability. In Case A, the patient with Down syndrome was treated with an antidepressant agent because symptoms such as social withdrawal were thought to be part of a depressive illness. A depressive disorder was also considered in Case C, the patient with pica, and
an SSRI was selected to treat symptoms of depression as well as compulsive eating behaviors.

Included in the spectrum of eating disorders noted in DSM-IV are behaviors such as Rumination and Pica. These disorders are frequently seen in childhood but are also found in persons with moderate to severe intellectual disability. Rumination involves chronic regurgitation of food without associated GI disturbance.\textsuperscript{8,13} Fredericks et al.\textsuperscript{6} note that up to 10% of institutionalized persons with severe or profound mental retardation may exhibit rumination. Chronic regurgitation can be associated with gastroesophageal abnormalities. A pathophysiological cause of abnormal eating behavior should be sought before the diagnosis of rumination is made. A recent survey of adults with severe intellectual disability in an institutional setting revealed a high prevalence of dysphagia and GI dysfunction as cause of the chronic regurgitation in that population. Chronic rumination often results in the proliferation of dental caries and the development of periodontal disease. The dental problems that result from chronic rumination may also lead to additional abnormal eating behaviors. As seen in Case A, tooth extraction may have precipitated the feeding difficulties in the patient with Down syndrome. Dental problems in individuals with mental retardation may cause, perpetuate or be a consequence of feeding difficulties in this population.\textsuperscript{17}

Pica, or scavenging behavior can be a serious eating disorder in patients with intellectual disability. One study recognized a prevalence rate as high as 9.2% in a population of institutionalized adults with mental retardation.\textsuperscript{9} Similar prevalence rates have been reported elsewhere.\textsuperscript{15} Case C illustrates how individuals with this eating disorder can consume both food and non-food items. Reports of serious medical complications, sometimes requiring surgical intervention, and even death highlight the seriousness of this disorder.\textsuperscript{10} In addition, these behaviors can disrupt previously stable living environments and interpersonal relationships. As was noted in Case C, the patient had been living with his care providers for approximately 15 years without significant problems until the eating behaviors threatened his relationship with his neighbors, individuals at his vocational program, and his care providers.

In summary, eating disorders occur in patients with varying degrees of mental retardation as well as developmental disabilities such as autism. They may be typical or atypical in their presentation. Abnormal eating in patients with mental retardation or developmental disabilities may be difficult to diagnose as an eating disorder because of the patient’s inability to express body image distortion. The diagnosis of the eating disorder will, ideally, find the core psychopathology of a morbid fear of fatness and relentless drive for thinness in addition to ruling out clear medical causation. For other patients, the abnormal eating behaviors may be a consequence of other psychiatric disorders such as affective illness or obsessive compulsive disorder.

The patients may respond well to treatment with a multimodal therapy and appreciation of the strengths as well as vulnerabilities of the intellectual developmental disorder. There is no reason to believe that patients will not benefit from principles and practices of eating disorder treatment, with an addition of pragmatic use of antidepressants and gastrointestinal medications. Further research is needed for a better understanding of eating disorders in patients with mental retardation and developmental disabilities.

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