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Pediatric Obesity Treatment in Children With Neurodevelopmental Disabilities:

A Case Series and Review of the Literature

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Abstract

Obesity can affect any child, but it occurs disproportionately in children with developmental disabilities. Treatment efforts, however, have focused primarily on nondisabled children, and more research is needed to determine how current approaches can be modified for youth with neurodevelopmental disabilities. This article briefly reviews what is currently known about obesity treatment in these children and presents a case series describing methods employed by a family-based, multidisciplinary weight management program in the treatment of obesity. Lessons learned from clinical experience are also discussed, with implications for collaborating with families of children with disabilities in treatment, establishing healthy routines and schedules, setting the pace of treatment progression, and minimizing disruptions in the behavior change process. Though there are no expert recommendations specifically tailored to obesity treatment in children with neurodevelopmental disabilities, existing clinical programs such as the one described here can be adapted to better meet the needs of this underserved population. Further research is warranted to determine the most effective methods for addressing obesity in these children, as has been specified as a national health priority.

Keywords

pediatric; obesity; obesity treatment; development; autism

Introduction

Pediatric obesity rates have more than tripled in the past 3 decades^{1–4} and will remain epidemic unless there are effective treatments. Obesity can affect any child, but it occurs disproportionately in children with developmental disabilities (autism spectrum disorder, Down syndrome, cerebral palsy, intellectual disability).⁵ In the presence of obesity, children with developmental disabilities not only have a heightened risk for weight-related comorbidities (eg, dyslipidemia, insulin resistance, sleep apnea, hypertension) but also have an even greater risk for developing secondary conditions related to their primary disability, such as fatigue, chronic pain, muscular impairment and deconditioning, social isolation, depression, and difficulty performing activities of daily living.^{6,7} Efforts to treat pediatric

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obesity have focused almost exclusively on nondisabled children,⁸ with very little attention on their developmentally disabled counterparts.⁵ Treatment for this population may require adaptations to existing programs and a high level of engagement from the child's family.⁵ As children with disabilities account for approximately 9.2% (6 million) of school-aged children in America,⁹ it is imperative that treatment providers adapt standard approaches to address obesity in all populations.

In this report, we (a) briefly summarize what is known about obesity in children with neurodevelopmental disabilities (NDDs), (b) present 3 case studies from a multidisciplinary pediatric obesity treatment program, and (c) highlight lessons learned through practice. Excluded from this overview are children with genetic abnormalities associated with obesity (Prader–Willi syndrome, Bardet–Biedl syndrome, etc), as their treatment needs are likely to be different.

Pediatric Obesity and Children With Neurodevelopmental Disabilities

We searched Medline (PubMed) and PsycINFO for English-language studies published between 1980 and 2012 regarding pediatric obesity and weight management in children with NDDs, autism spectrum disorder, and cognitive and developmental delays. Search terms included pediatric obesity treatment, childhood obesity treatment, pediatric nutrition, and pediatric physical activity. Each of these terms was cross-searched with: neurodevelopmental disability, autism, Down syndrome, cerebral palsy, and intellectual disability. We expanded our search to include reviews of activity and nutrition behaviors linked to obesity in this population, as well as those by authors known in the field and hand-searched reference lists from original articles. Studies were included if they were conducted in a pediatric age group or pertained to pediatric obesity, and included any of the aforementioned search terms in the research design, data analysis, or the manuscript. Given the scarcity of literature identified in the search, interventions, correlations, reviews and commentaries were considered. Full articles were obtained if abstracts appeared to meet inclusion criteria or if there was insufficient information to determine inclusion. Articles were then independently reviewed by 2 investigators (MBI, JAS) against inclusion/exclusion criteria. We identified 156 articles, of which 32 were included, having examined pediatric obesity and its correlates in children with developmental disabilities. Articles and studies were not rated; non-peer-reviewed sources were not included.

Rates of obesity are higher among children with NDD compared with those without disabilities,^{6,10–12} even after controlling for sex and race/ethnicity.⁵ Obesity is significantly more common in cognitively disabled children compared with those with physical disabilities, and is a major public health concern for this population.⁵ Similar to obese children without developmental disabilities, severity of obesity worsens as children with NDD grow older, increasing the likelihood that they will become obese adults. These children likely share the same risk factors as their nondisabled peers, with greater implications for mental health, self-esteem, body image, stress, and ability to socialize. Thus, there is a great need to address the contributors of obesity specific to children with NDD, including identification of unique activity and nutrition habits, family knowledge, and the child's ability to interact socially. Specific challenges are outlined in greater detail below.

Activity

Children with developmental disabilities are less physically active compared with children without disabilities,¹³ and their health behaviors are often markedly different.¹⁴ Numerous studies indicate that disabled individuals are more likely to be sedentary^{15,16} and that they often have significant barriers to activity participation.^{17,18} Evidence suggests that only one

third (35.4%) of adolescents with disabilities meet daily recommendations for physical activity,¹⁹ and physical and cognitive limitations related to their disability may impair the ability to participate in sports, recreational pursuits, and exercise.²⁰ In developmentally disabled youth, sedentary behaviors such as watching television or using video games and computers are reportedly higher, and they are less likely to participate in recreational activities because of impaired function²¹ and difficulties with motor coordination during complex games and sports.^{22,23} Barriers in the built environment present limitations as well,²⁴ such as a lack of opportunities and accessible equipment.^{13,25} Social barriers are also impediments to activity in children with NDD, as they may be deterred from activity participation because of poor social support from peers who do not have disabilities.^{23,25} To address these issues, the American Academy of Pediatrics' Council on Children with Disabilities released a clinical report advocating activity participation for children with special needs, with strategies to minimize injury risk. Recommendations from this report encouraged parents, children, and medical providers to collaboratively identify specific barriers to activity participation, while considering the child's health, personal preferences, safety, and availability of activity opportunities.²⁰

Nutrition

Children with developmental delays are more likely to have chronic difficulties with feeding,^{26–28} and up to 80% have reported nutritional challenges.²⁶ Most common in these children are gastrointestinal and accompanying sensory and behavioral issues, airway compromise, or oral motor limitations.²⁹ Multidisciplinary approaches are essential for recognizing complex feeding behaviors that may result from food and texture aversions. These behaviors are particularly problematic in children with autism spectrum disorder and may lead to inadequate nutrition.³⁰ Feeding issues related to the child's disability may include a preference for a limited selection of foods that provide little nutritional variety (ie, only choosing to eat French fries or chicken nuggets for meals)³¹ and a tendency to overeat, which may contribute to weight gain. In the context of obesity treatment, such issues may present difficulties, as children with developmental disabilities may express greater resistance to trying new foods. Given that many parents, teachers, and behavioral therapists use food to soothe or reinforce good behavior in children with NDD,³² parents may also struggle with the implementation of nutritional changes. Management of long-term feeding difficulties in developmentally disabled children should be based on the child's developmental readiness, not chronological age,²⁷ and should focus heavily on parenting, support, and family education.³³ For the treatment of obesity, the family's role is crucial in establishing a positive feeding environment for the child, assessing which feeding practices need to be modified, and improving overall nutrition.

Current Recommendations for Pediatric Obesity Treatment

In 2007, the American Medical Association and the Centers for Disease Control and Prevention released expert recommendations for the treatment of pediatric obesity,^{34,35} suggesting a multi-disciplinary, behavioral-based approach incorporating a child's family into the behavior change process. Such comprehensive behavioral interventions are considered the "gold standard,"³⁶ as inclusion of the child's family into treatment^{37–43} acknowledges parents as authority figures who guide the weight-related behaviors of their children. Clinicians in these settings work with parents to indirectly influence children's behaviors (especially younger children), and interact more directly with the children as they grow older and have greater autonomy. However, treatment of special populations, such as children with NDD, is not mentioned in the expert recommendations, and our search yielded no formal recommendations regarding obesity treatment in children with NDD.

Children with NDDs who exhibit intellectual impairments may have limited understanding of their health behaviors and risks; school-based programs recommend health behavior curricula uniquely tailored to the child,³² which is consistent with the principles of patient-centered care. Thus, as it relates to clinical obesity treatment and the intensive nature of such programs, it is important to recognize the unique behaviors and capabilities of each child and incorporate their caregivers in the treatment process. Parental participation is essential, as modeling, guidance, feedback, stimulus control, and clear goal setting are highly recommended when addressing nutrition and fitness behaviors in exceptional children.³²

However, increased responsibility pertaining to nutrition and activity may overwhelm a parent already managing frequent physician visits, therapies, medications, and behavioral challenges. Coordinating treatment and participating in an intensive behavioral-based obesity program may differentially affect the families of children with NDD. These families report significant financial burdens because of home care needs, care coordination, loss of parent income,⁴⁴ and increased risk of poverty.⁴⁵ Medical costs for children with special health care needs account for more than 41% of overall child health care expenditures in the United States,⁴⁶ as these children often require frequent attention from a variety of medical providers and behavioral experts.⁴⁷ Mobility and transportation issues may also influence treatment adherence and ability to access treatment options.⁶ Therefore, obesity treatment approaches should strive to minimize these barriers by providing family-centered care and improved access to support services specific to each family's needs.

Obesity Interventions in Children With NDD: Experience and Practice

Brenner FIT Program

The Brenner FIT (Families In Training) Program^{48–50} is a multidisciplinary, pediatric, family-based weight management clinic, with a team of pediatricians, dietitians, family counselors (licensed clinical social worker and a marriage and family therapist), a physical therapist, and an exercise physiologist. Children who are obese, aged 2 to 18 years, are seen by referral from their primary care provider, with a body mass index (BMI) 95th percentile for age and gender by standard growth charts⁵¹ and one or more obesity-related comorbidities. Treatment occurs over 12 months, beginning with biweekly visits with the multidisciplinary team and progressing to less frequent visits based on the needs of each family. Central to the Brenner FIT method is the use of motivational interviewing,⁵² a patient-centered communication strategy used to enhance motivation for change as families identify habits on which to focus during treatment. Behavioral therapy techniques are also crucial in helping families achieve stimulus control, goal setting, and monitoring their weight-related behaviors.⁵³ The Brenner FIT program is described in greater detail elsewhere.^{48–50,54}

Brenner FIT and Special Populations

The Brenner FIT program continuously reviews its patient population and clinical outcomes through its clinical database.⁵⁵ This database indicated that special populations existed within the referral area for whom modified treatment approaches were needed. As a result, Brenner FIT established a Spanish-language program, *Mejor Salud, Mejor Vida* (“Better Health, Better Life”)⁵⁴ under the direction of a bilingual case manager, and a telemedicine program, *TeleFIT*⁵⁶ for rural and underserved families otherwise unable to receive obesity treatment because of geographical barriers. Most recently, we determined that approximately 5% of patients referred for treatment were children with NDD. Treatments with these families may require more intensive strategies than outlined in expert recommendations.³⁴ Below, we provide 3 examples of how treatment was targeted and

modified for children with NDD and their families. Names, identifying characteristics, and other details have been changed to protect the identity of patients and their families.

Case Scenario 1: Adam

Adam, a nonverbal 6-year-old Caucasian boy presented to Brenner FIT with autism spectrum disorder, developmental delay, hyperlipidemia, hypertriglyceridemia, and acanthosis nigricans. He was above the 99th percentile for age and gender (BMI = 34.9 kg/m²; z-score = 3.098). Adam was accompanied by his mother and father, who identified texture sensitivity and intolerance to most solid foods as Adam's primary dietary challenges. A pediatric eating assessment had been conducted with Adam previously while in treatment with a developmental pediatrician, dietitian, psychologist, and speech therapist. At intake, the Brenner FIT dietitian completed a functional analysis of Adam's eating behaviors, including food texture sensitivities, tolerance, and food preference/avoidance. The treatment team considered Adam's sensitivities to food throughout his treatment progression and recognized the need to move at a pace that Adam could tolerate. With the Brenner FIT team, Adam and his family addressed a variety of food issues and worked to increase participation in physical activity.

Nutrition

Adam's mealtime calorie intake was consistent and well documented because of the routine and controlled nature of meals. Thus, the dietitian could provide precise recommendations to improve caloric intake from carbohydrates, proteins, fats, and overall nutrient quality. Specific recommendations were made to decrease Adam's total daily caloric intake and calories consumed from carbohydrates, while also increasing the percentage of calories consumed from protein and unsaturated fats. Adam's family followed these recommendations and reported an increase in offerings of modified forms of chicken breast and nut butters, with decreases in refined grains, cereals, fried potatoes, and desserts.

Among the greatest challenges was creating a behavior plan that would be least disruptive to Adam. Feeding difficulties were identified, including aversions to texture, appearance, and smell, and extreme limitations to nutrient variety. Adam's parents presented foods consistently on the same cafeteria-style segmented tray at lunch and dinner, with a set location for each food item. Approximately 80% to 90% of Adam's meals were in the form of baby foods. Using the parents' own knowledge of their child's behavior and food preferences, the Brenner FIT team worked with parents to slowly incorporate new foods, with lower energy density, while maintaining the familiar presentation and approximate volume of food. Despite lack of immediate change, Adam's parents were encouraged to continue offering new foods, and Adam was later able to tolerate new options at a slow pace. It became evident that Adam had moments of marked resistance to change, but he also appeared to be more accepting of change at other times. During these "windows of opportunity," Adam learned to accept new textures and smells, and expressed increased interest in foods that his parents were eating. Introduction of new foods was more manageable when paired with a food that Adam was already comfortable consuming, even more so during Adam's "windows of opportunity." Adam's parents eventually could offer new foods without having to pair them with familiar ones. After 36 months, Adam was no longer consuming baby foods. The family had successfully introduced new proteins, increased fiber and variety of fruit and vegetables, and decreased the amount of high-fat, low-fiber carbohydrates in his diet.

Adam's parents also indicated that snacking was a significant challenge, as he continuously requested snacks during the day. Often, his parents would provide snacks after completion of tasks as rewards, to assuage disruptive behavior, and as an expression of love and

acceptance. The family eventually chose to address snacking behaviors by only allowing snacks during routine times throughout the day, and found other non-food-related distractions to entertain Adam.

Activity

A physical therapist helped the family address Adam's lack of physical activity by including his parents and in-home aides in creating activity routines, play schedules, and ideas for non-food distractions. Because of Adam's limited attention span (60–90 seconds), in-home activity was a challenge. A picture exchange communication system, an alternative communication system widely used for children with autism^{57–59} (<http://www.pecs.com>), allowed Adam to direct himself from one activity to another, which also decreased episodes of snacking and negative behavioral responses.

Motivational interviewing was essential in this process to identify the family's specific interests and relied on them to determine the direction and pace of care. At last check, his BMI z score had decreased to 2.724 (BMI = 40 kg/m²).

Case Scenario 2: Tommy

Tommy is a 16-year-old Caucasian youth with Asperger syndrome, generalized anxiety disorder, attention deficit/hyperactivity disorder, impulse control disorder with intermittent explosive outbursts, obsessive-compulsive behaviors, developmental delays, hyperlipidemia, musculoskeletal pain, and obesity above the 99th percentile for age and gender (BMI = 44.0 kg/m², z-score 2.892). Tommy was accompanied by his mother, maternal grandmother, and a dedicated case worker.

Nutrition

The family chose to focus on mealtime behaviors and created short-term goals with team support. At start of treatment, Tommy was eating 3 to 4 meals and numerous snacks daily. The team worked with the family to establish structured meal and snack times to decrease total eating episodes. These routines also helped Tommy eat more meals and snacks at the table, thereby reducing television distractions while eating. Meal planning was also a focal goal, which allowed Tommy to anticipate upcoming meals and participate in food selection. As in many other families whose children have autism spectrum disorder, structure at the dinner meal was already in place, allowing the family to focus on what was being served. Tommy's mother began offering more fruit and vegetables and fewer carbohydrates at meals. In each step of the change process, Tommy was involved in choosing new foods, which may have aided his acceptance of most changes. Although Tommy did not exhibit sensitivities to food texture, his mother was cautious and most often chose foods Tommy would likely tolerate. The team supported Tommy with changes by progressing at Tommy's pace, working with his mother and grandmother to plan meals and decrease restriction and pressure, capitalizing on the structure already in place.

Activity

Before beginning treatment, Tommy and his family attended the YMCA together 3 days each week. Thus, the team's focus was providing support for the existing routine, and encouraging the family to address barriers when participation in activity began to wane.

Unlike Adam's case, Tommy did not show “windows of opportunity,” but the family intensified their goals based on their own readiness, while also relaxing goals during times of stress (eg, poor parental health, escalation of behavioral problems, or worsening of his depression). Because of Tommy's age and cognitive ability, he was included in planning

most habit changes, although responsibility for implementing changes relied on caregivers. In collaboration with Tommy's developmental pediatrician and psychologist, the family could better manage Tommy's weight-related behaviors and implement changes at home. Through the first 4 months of treatment, he maintained his BMI and BMI z-score.

Case Scenario 3: Edward

Edward, a 12-year-old African American boy, presented for treatment with diagnoses of mild mental retardation, attention deficit/hyperactivity disorder, depression, acanthosis nigricans, hypertriglyceridemia, and obesity above the 99th percentile for age and gender (BMI = 41.16 kg/m², z-score = 2.7). Edward was accompanied to treatment visits by his adoptive mother. Edward had experienced abuse early in life, and often exhibited violence toward his adoptive family. Edward's medications included oxybutynin, metadate, ziprasidone, and carbamazepine, with side effects, including loss of appetite and weight gain. The use of such medications was reviewed by the Brenner FIT physician; no alterations were recommended. At the time of his referral, medications for Edward were managed by a psychiatrist and an in-home aide, and he was awaiting intensive in-home therapy.

Nutrition

The team worked with Edward's mother to make changes that were within her control. Attempts to limit his food intake often led to violent outbursts, though she reduced sugar content of beverages and offered vegetables more often during meal and snack times. Edward participated in selecting vegetables that he preferred and did not display sensitivities to food texture, though he ate all meals from the same blue bowl.

Activity

Edward's mother provided time for him to play outside with friends for more than an hour on most days, and he particularly enjoyed basketball and football. This increased Edward's overall participation in activity and reduced his television viewing. Later, as activity lagged, Edward began walking 2 or 3 days each week with a family friend.

Because of his behavioral challenges and intellectual disability, Edward's progress was slow. With the family's consent, the treatment team met with Edward's teachers to address behaviors within the school setting that his parents had less control over. The highly structured nature of Edward's classroom was a benefit to the treatment process and, thus, did not need to be intervened on. Changes were made primarily through his mother, and his progress depended on his depressive symptoms. Greater progress occurred during times of stability, where he tended to struggle with changes when depression worsened. During the first increase in depressive symptoms while attending treatment, Edward resumed screen time activities, stopped playing with friends, and refused vegetables offered at meals. The treatment team supported his family in continuing to make many environmental changes despite Edward's own reluctance, but his physical activity was limited by risks associated with new medications. Edward recovered well from his depressive episode and later resumed progress toward his nutrition and activity goals. However, his depression returned and violence escalated. After 7 months of treatment, Edward's behavior escalated again, and the family secured more intensive behavioral support. During this time, Edward's appetite was reported to be "out of control," leading his mother to place a lock on the refrigerator. As Edward's response to habit change threatened the safety of his family, it was determined that his emotional health was a priority. In collaboration with the team, Edward's family decided to leave treatment to concentrate on managing his violent behavior, with the understanding that they could return at any time.

Discussion

Tertiary care programs can adapt treatment methods that meet the unique needs of each child with NDD and his or her family; lessons learned from practice may also guide methodology. This case series highlights these lessons for clinicians attempting weight management in children with NDD:

- Motivational interviewing and constant collaboration with families are key for facilitating behavior change and allows them to guide the change process.
- Provide families with education and support to establish realistic expectations and include all relevant members of the clinical team throughout the treatment process as needed.
- If children cannot participate meaningfully, it may be necessary to work exclusively with parents to implement environmental, food, and activity changes without distractions during treatment visits.
- Whenever possible, the child should be included in the treatment process. Parents and clinicians should include the child when making decisions both at home and in clinic. Providing a limited range of options may be most supportive and best received by the child.
- Allow families and children to set the pace of their behavior change, with consideration for the child's comfort and capabilities, recognizing that progress may be slow.
- Develop an awareness of food and texture challenges that may influence the child's response to nutrition goals, and allow the child to participate in planning meals and snacks at a developmentally appropriate level.
- Build goals around the family's established structure and routines to increase the child's comfort with changes to nutrition and activity behaviors.
- Equip families with resources to help manage behaviors that may complicate implementation of goals; work with parents to increase confidence as they anticipate and respond to behavioral challenges.
- Collaborate with the child's other medical providers, teachers, and case workers to provide consistent care during the behavior change process.
- Develop a relationship with the child and the family to recognize potential "windows of opportunity" for greater progress, or decrease the intensity of treatment when families are experiencing difficulties.
- Use interdisciplinary approaches allowing collaboration among treatment staff when addressing complex feeding and activity issues.

Conclusion

Individuals with NDD are likely to experience health-related complications due to obesity,¹⁵ and eliminating health disparities in populations with increased vulnerability to chronic conditions is a national priority.¹⁵ However, a review of the literature demonstrates that research strategies in pediatric weight management have focused almost entirely on nondisabled children, creating a substantial void in the literature on successful interventions for disabled youth.^{6,11} Since pediatric obesity treatment programs are likely to receive referrals for children with NDD, clinicians must be equipped to deliver effective care for them and their families. In the absence of pediatric obesity treatment recommendations

specifically for this population, lessons learned in practice, such as those presented in this case series, may be of value to clinicians attempting to provide care for children with NDD and their families. Recommendations for the treatment of obesity in this population would advance the efficacy of care provided and guide clinicians in adapting existing treatments to better meet this population's needs.

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