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Targeting parents for the treatment of pediatric obesity in boys with Duchenne muscular dystrophy: A case series

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Abstract

Obesity is a major public health concern in children. Obesity occurs frequently in boys with Duchenne muscular dystrophy (DMD), complicating treatment and impairing functioning. Parent-focused interventions to facilitate weight loss have been successful in other pediatric samples but have not been studied with this population. The current investigation examined the feasibility and potential efficacy of parent-focused treatment to improve healthy eating and physical activity of parents and eating and weight in their sons with DMD. Three families participated in this case series. Resulting changes in body weight among boys with DMD were an outcome variable. Findings indicate inconsistent changes in boys' weight, decreases in parent weight, increases in healthy foods available in the home, and increases in children's perceived quality of life. Participant ratings of treatment suitability and satisfaction were generally favorable. These preliminary findings support the use of parent-focused psychoeducation for the treatment of obesity in children with DMD.

Keywords

Childhood obesity; Duchenne muscular dystrophy; parenting; weight loss; chronic illness

Introduction

Duchenne muscular dystrophy (DMD) is a congenital muscle dystrophy affecting approximately one male child in 3500 and accompanied by a loss of muscle mass typically occurring during pre-adolescence. Approximately 44-54% of boys with DMD will become obese by age 13 (1) and increased weight complicates their medical condition and treatment. Weight loss treatment may be especially beneficial for individuals with physical disabilities

like DMD. Maintaining normal weight in DMD helps sustain ventilatory function and improves all aspects of movement, including wheelchair transfers. Although the possibility of muscular degeneration might contraindicate weight loss treatment, Edwards et al. (2) observed no muscle deterioration in an obese 14-year-old with DMD who lost 37 kg in one year through dietary restriction, suggesting that supervised weight loss may improve quality of life and medical care without exacerbating the muscular dystrophy.

Several investigations support the efficacy of parent-focused treatment for pediatric obesity, in which parents exclusively participate in treatment visits without their children (3). Parental focus is thought to be beneficial because of the influence that parents have in household food availability, the caloric density of foods served in the home, and modeling of healthy eating and exercise behaviors. Children with DMD and other mobility impairment may be ideal candidates for parent-focused treatment because, due to decreased motor function, DMD results in increased reliance on caregivers. Furthermore, parent-only participation could mitigate time constraint and transportation issues for boys with DMD using wheelchairs.

The current case series investigation sought to examine the feasibility and preliminary efficacy of a parent-focused treatment for co-occurring obesity in children with DMD.

METHODS

Participants

Participants were three families with a son diagnosed with DMD. Ages at study entry were eight, thirteen, and thirteen. Boys were considered obese if their weight was at or above the 90th centile according to the DMD weight chart (4)¹. Eligibility was limited to non-ambulatory boys who were wheelchair dependent at baseline.

Measures

Child weight was measured using a wheelchair accessible digital scale. Parent weight was recorded at all sessions using a calibrated digital scale. Family food environment was assessed by parental completion of the Food Shelf Inventory (FSI), which surveys the foods available at home. High criterion validity for the FSI has been previously demonstrated (5).

To measure children's quality of life, the Pediatric Quality of Life Inventory (PedsQL) Child Report and Parent Report for Children were administered to all participants. The reliability and validity of the PedsQL has been observed in a previous study (6).

Treatment feasibility and motivation for treatment were assessed using a two-item questionnaire asking parents' perceived suitability and predicted success of the program (7). Parents' verbal feedback was also solicited throughout and following treatment.

¹To accurately measure obesity while allowing for progressive muscle loss, a weight for age chart for DMD was developed (4). Based on assumed decline in muscle mass per year of age, this chart provides a more flexible definition of obesity for boys with DMD.

Design

Participating families were recruited from a muscular dystrophy clinic at an academic health center. Assessment measures were administered at baseline and post-treatment visits. This investigation was approved by the University of Minnesota Institutional Review Board.

Intervention

Treatment consisted of 20 one-to-one meetings with one parent from each family and the first author, a doctoral student therapist. One-hour sessions were administered over six months, with visits occurring weekly for the first twelve sessions, then bi-weekly for eight. Written treatment manuals were provided to participants.

Five main foci of treatment were emphasized in parent sessions and written materials. Treatment was modeled according to childhood obesity weight loss and prevention manuals developed by Epstein (8) and Boutelle (9). Goals related to energy expenditure were modified from previous treatment models to include both appropriate and manageable movement goals for non-ambulatory boys with DMD and to provide suitable examples for energy expenditure including pediatric standing frames and dancing while in wheelchairs.

Treatment topics included healthy eating environments, the Traffic-Light Diet (10), behavioral change techniques, weight management, and parenting techniques such as positive reinforcement. The Traffic Light Diet provides guidelines for GREEN foods that are high in nutrients and low in fat and sugars; RED foods high in fats and sugars and low in nutrient density; and other YELLOW foods that fall between the two. Goals included decreased availability and consumption of foods with high fat and high sugar content, increased availability and consumption of foods high in nutrients, and decreased calorie goals. Behavioral change techniques taught parents to model self-monitoring of eating and activity for their child with DMD. Parenting techniques and the use of verbal and behavioral positive reinforcement techniques were emphasized, including token economy schedules. Final sessions focused on weight maintenance, review of positive changes, and strategies for the ongoing use of acquired skills.

Results

Children's weight outcomes varied with one child's weight decreasing, one remaining stable, and one increasing over the six-month treatment period². Body weights for all parents decreased from baseline to post-treatment. Both parent and child weight changes at pre-to post-treatment are displayed in Table 1. At baseline, parents rated on a six-point scale that they thought the treatment would be suitable (mean =4.4) and successful (mean =4.8).

Food availability data, shown in Figure 1, indicated that all three families increased the availability of low fat foods while high fat food availability was variable over the six months. Results from the quality of life assessment (Fig. 2 and 3) demonstrated that all three boys

²Of note, the child whose weight increased by approximately 10 kg was the only participant who was taking steroid medications for DMD throughout the study.

and two of the three participating parents reported an overall increase in the boys' quality of life, particularly related to physical health, at the end of treatment.

Discussion

The aim of this study was to investigate the feasibility and preliminary effectiveness of parent-focused obesity treatment for three boys with DMD and, more broadly, children with physical disabilities. Findings suggest preliminary support for the potential efficacy of this intervention. Treatment response was favorable and all enrolled families completed the protocol. Outcome data indicate increases in children's quality of life and the number of low fat and nutrient-dense foods available in families' environments. Although weight loss findings were inconsistent among boys with DMD, weight loss in all three participating parents suggests a positive effect on parental lifestyle changes. These results also imply that the intervention may have a direct positive effect on child quality of life independent of weight loss.

This study is the first to apply an obesity treatment protocol previously effective in able-bodied individuals (11) to a specific population of non-ambulatory boys with DMD. All three participating parents verbally reported satisfaction with accomplishments including healthy lifestyle behaviors. Parents acknowledged changes that included substituting high fat items with low fat items, involving their children in the selection of healthier snacks and meal planning, and incorporating exercise into daily activities. Some aspects of the results were not clear. For example, parents differed in their report of available food at the end of treatment with one reporting increased, one reporting reduced, and one reporting the same number of RED foods. The extent to which these inconsistencies were the result of differences in compliance and the potential impact on outcome is uncertain. Constructive participant feedback included need for better manual organization, DMD specific nutritional knowledge, and child engagement.

Limitations of the current study include the small sample size of three families, a limitation that reflects the pilot nature of this investigation and the challenges of recruiting DMD families. Clearly, a larger randomized controlled study is needed to examine the efficacy of parent-focused weight loss treatment for children with DMD. Tele- or video-counseling sessions in future trials may help with enrollment of participants with limited mobility, and for those who live long distances from medical centers. Delivering treatment electronically might also facilitate recruitment for larger randomized control trials with a relatively rare condition.

The lack of consistent weight loss across the three participants with DMD may partially be due to the modification of activity requirements, a main component of previously studied treatment (11), as well as the impact of other DMD treatments, particularly steroids, on weight. Furthermore, younger ambulatory boys were excluded from the study to assure a more homogeneous participant profile, but those boys may respond more dramatically to the intervention based on greater ability to increase expenditure of calories. Future investigations should examine the use of these interventions in younger patients with DMD who have more mobility in order to establish positive eating habits prior to wheelchair usage.

One of the most important implications of this study is its applicability to the underserved population of obese patients with DMD. Although boys with DMD and their families face many serious challenges, weight loss interventions have the potential of improving quality of life. One of the most notable findings is that per participating boys' report, quality of life was improved regardless of changes in weight status.

In light of recent advancements in ventilatory support (12), life expectancy for boys with DMD has increased, with affected individuals often living more than 30 years. Based on the preliminary results of the current study, emphasis on healthier eating and more feasible lifestyle activity can be expected to improve mobility, daily functioning, and emotional health in boys with DMD. Importantly, results from the current case series indicate that a focus on healthy lifestyle behaviors positively influenced the physical health of boys with DMD as was rated by all three of the participating boys and two of the participating parents. Results from this study suggest that parent-focused weight loss treatment is helpful to families with DMD and warrants further study in future investigations.

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FIGURE 1.

Food Shelf Inventory.

* This questionnaire surveys the foods available within a home; parents respond yes or no to 94 possible items according to various nutrient categories of foods that might be present in their house at that time.

FIGURE 2.
Parent report of child's quality of life.

FIGURE 3.
Child report of quality of life.

TABLE 1

Pre- to post-treatment weight change in kilograms.

	Child*	Parent**
Family 1	9.98	-1.81
Family 2	-5.08	-2.72
Family 3	2.00	-4.54

* Children at both pre- and post-treatment were all classified as >90% ideal weight for age according to the Griffiths and Edwards (1988) chart;

** parents at both pre- and post-treatment were all classified as overweight.