Parent Support Improves Weight Loss in Adolescents and Young Adults with Down Syndrome

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Objective To assess whether parent training in behavioral intervention, combined with a 16-session nutrition and activity education program, would improve weight loss relative to nutrition and activity education alone in adolescents and young adults with Down syndrome.

Study design Twenty-one patients with Down syndrome aged 13-26 years with a body mass index ≥85th percentile were enrolled and randomized to a 6-month nutrition and activity education intervention (n = 10) or to a nutrition and activity education+behaviorial intervention (n = 11), and followed for 6 months after the active intervention period (1-year follow-up). The primary outcome measure was body weight; secondary outcomes included percentage body fat by bioelectric impedance; intake of fruits, vegetables, and energy-dense low-nutrient snack food (treats) by 3-day food record; and moderate/vigorous physical activity by accelerometry.

Results At 6 months, mean body weight in the nutrition and activity education+behavioral intervention group was 3.2 kg lower than that in the nutrition and activity education group (95% CI, 1.0-5.5 kg; P = .005). Mean group differences were sustained at 1 year (3.6 kg; 95% CI, 1.4-5.9 kg; P = .002). At 6 months, moderate/vigorous physical activity time increased by an average of 18 minutes/day compared with baseline in the nutrition and activity education+behavioral intervention group (P = .01) and decreased by 7 minutes/day in the nutrition and activity education group (P = .30). These changes were largely maintained at 1 year, but were not statistically significant. Vegetable intake in the nutrition and activity education+behavioral intervention group exceeded that in the nutrition and activity education group by a mean of 1.6 servings at 1 year (P = .009), but not at 6 months. No between-group differences were observed for percentage body fat or consumption of fruits or treats.

Conclusion Parent-supported behavioral intervention appears to be a successful adjunct to a 6-month nutrition education intervention in achieving weight loss in adolescents and young adults with Down syndrome. *(J Pediatr 2013;163:1402-8)*.

The prevalence of childhood obesity has increased dramatically over the last 20 years in the US, with almost 1 in 5 children considered obese.[1] Obesity prevalence is also high in children with intellectual and developmental disabilities,[2] particularly those with Down syndrome. One study of 81 adolescents with Down syndrome estimated the prevalence of obesity at 31%.[3] Data on the consequences of obesity in youth with Down syndrome are lacking, but these youth are likely faced with similar health risks as the general population.[4]

Research is needed on weight loss interventions that address the cognitive and literacy limitations of adolescents and young adults with Down syndrome. Family-based interventions, which have been shown to be efficacious in randomized controlled trials with typically developing children, use individualized diet and physical activity plans for gradual weight loss, along with behavioral training that teaches parents to use diet and activity monitoring, stimulus control, goal setting, and positive reinforcement.[5] To our knowledge, no such weight loss programs for youth with Down syndrome have been tested.[6] Although youth with Down syndrome live in the same obesogenic environment as the general population, their unique needs and challenges may make them more susceptible to the adverse effects of typical obesity-related risk factors. They also may be vulnerable to additional risk factors not shared by children in the general population by virtue of their limited cognitive abilities, altered body composition, and challenges with motor coordination and balance.

We conducted a pilot randomized controlled trial of a family-based weight loss intervention with adolescents and young adults with Down syndrome living at home. Our primary aim was to determine whether parent training in behavioral intervention, combined with a 16-session nutrition and activity education program, improved weight loss compared with nutrition and activity education

%fat	Percentage body fat

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Supported by the National Institutes of Health (DK070627, DK046200, and HDP30HD004147) and the John W. Alden Trust. The authors declare no conflicts of interest.

Registered with ClinicalTrials.gov: NCT01256112.

0022-3476/$ - see front matter. http://dx.doi.org/10.1016/j.jpeds.2013.06.081

alone. Our secondary aim was to evaluate associated changes in percentage body fat (%fat), moderate to vigorous physical activity, fruit/vegetable intake, and high energy-dense/low nutrient-dense food intake.

Methods

This pilot randomized controlled trial was conducted between October 2007 and March 2010 at the University of Massachusetts Medical School's *Eunice Kennedy Shriver* Center. Participants were recruited through mailed flyers, postings by disability-related organizations, and physician referrals. Participants with Down syndrome met the following inclusion criteria: age 13-26 years, body mass index ≥85th percentile,[7] IQ 45-70, written physician approval, and a parent willing to attend sessions. The relatively wide age range was selected to facilitate recruitment and to collect pilot data on participants with Down syndrome that spanned the important transition years of adolescence to young adulthood. Exclusion criteria included use of appetite-altering medications, chronic gastrointestinal illness, untreated thyroid disorders, uncontrolled seizure disorders, or orthopedic or cardiac conditions that would preclude physical activity participation. Families were telephone-screened and then attended an enrollment visit (IQ testing, parent and child interview) to determine eligibility. Eligible participants provided informed assent; parents provided informed consent. The protocol was approved by the University of Massachusetts Medical School's Institutional Review Board.

Participants and parents were interviewed by a registered dietitian, who obtained a diet history and developed a diet plan for each participant that specified a 250-kcal/day deficit, designed to yield a 1/2- to 1-pound weekly weight loss. This conservative caloric goal was based on the American Academy of Pediatrics recommendations for adolescents, which we deemed developmentally appropriate for the participant age range. Parents were taught to use the diet plans with instruction and given an accompanying instructional guide.[8] Pictures provided a simple visual approach to daily diet planning, and a system of "tickets" and "coins" helped participants choose a daily allowance of discretionary calories.

A physical therapist evaluated the participants' ability to perform exercises in the program's physical activity plan. The plan, provided in a notebook with simple messaging and illustrations, prescribed flexibility exercises, aerobic activity (eg, brisk walking, dancing) for 5 days/week, and strength training with exercise balls/bands for 2 days/week. On the rare occasion that a participant was unable to perform exercises as prescribed, the exercise plan was modified.

Participants were randomized to 1 of the 2 intervention groups, with block size equal to the number of subjects in each wave[9]; group assignment was made in the order of enrollment by the research coordinator working from a printed list of assignments. Parents were not blinded to group assignment. Immediately after assignment, 3 families who reported schedule conflicts were permitted to join the other intervention group. These participants were flagged to evaluate the effect of this reassignment on the analyses.

Both interventions were conducted in 16 90-minute sessions delivered during the first 6 months of the intervention period. This active intervention period began with 10 weekly sessions in the first 3 months, followed by 3 months of tapered intensity (4 biweekly sessions, followed by 2 sessions that met every third week). Participants were tracked during a no-intervention follow-up in months 6-12. **Figure 1** (available at www.jpeds.com) shows the 3 separate waves that were designed to maintain group sizes of 4-5 participants.

Nutrition and activity education taught basic nutritional concepts and exercises through simple verbal instruction, demonstrations, activities (eg, games), and taste tests. Sessions were conducted by a dietitian and a therapeutic recreation specialist. Eight sessions covered nutrition, 7 sessions addressed physical activity, and the final session was a potluck celebration dinner. Participants were taught to make food choices associated with their diet plans, emphasizing consumption of fruits, vegetables, and low-fat dairy products; correct portion sizes; and healthy snacking. Physical activity sessions taught exercises from the participants' plans. All 15 sessions provided 40 minutes of instruction with parents present, a 10-minute break, and 40 minutes of practice and taste tests with the adolescent and young adult participants only. Parents attended the first 40 minutes and met separately as a group for informal support/discussion for the last 40 minutes.

The nutrition and activity education+behaviorial intervention included the foregoing nutrition and activity education activities (first 40 minutes), followed by 40 minutes of group training with parents, conducted by a behavioral specialist who provided instruction on behavioral strategies such as diet/activity monitoring, modification of "stimulus control" conditions at home, daily/weekly goal setting, and positive reinforcement. These strategies are used in family-based intervention research with typically developing children.[5,10] Although not required to make personal changes, parents were encouraged to model, facilitate, and reinforce healthy eating/activity for their offspring. Each full-group session began with participants sharing their goal accomplishments from the previous week.

Outcome data were assessed during the sessions. Staff who took the measurements were not blinded to group assignment, but their training stressed objectivity. All outcome measures were recorded at baseline, 10 weeks, 6 months, and 12 months, with additional weight and % fat assessments at 2, 4, 6, 8, 11, and 13 weeks. The primary outcome was weight (in kilograms). Secondary outcome variables included %fat, physical activity (minutes of moderate/vigorous physical activity), fruit intake (servings/day), vegetable intake (servings/day), and treat intake (kcal/day). The treat category included such items as candy, chips, nondiet soda, cake, cookies, ice cream, and so on. Participants were assessed while wearing light clothing without shoes. Height was measured to the nearest 0.1 cm with a stadiometer. Weight and body fat were measured with a bioelectrical impedance analyzer (BC-418 Segmental Body Composition Analyzer and Scale; Tanita, Arlington Heights, Illinois), using equations developed in the National Health and Nutrition Examination Survey.[11]