

Brief Report

Parents' perspective on weight management interventions for adolescents with intellectual and developmental disabilities

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Abstract

Background: Adolescents with intellectual and developmental disabilities (IDD) have high rates of obesity. However, little research has been conducted demonstrating effective strategies and barriers for weight loss or weight management in adolescents with IDD. Furthermore, parents play a large role in terms of weight management in children and adolescents with IDD, and their views should be taken into consideration when designing a diet and PA intervention for weight management.

Objective: The aims of this study are to better understand the parents' perspectives on the strategies and barriers for helping children and adolescents with IDD be successful in a weight management program and to identify how this information to guide future approaches.

Methods: Semi-structured interviews were conducted in 18 parents whose children had just finished a diet and PA intervention. Interviews were transcribed verbatim, and thematic analysis was performed.

Results: Parents reported a positive attitude toward the program, liked the convenience of the program, and felt that they learned beneficial strategies to encourage healthy habits in the home. Parents found time to be a major barrier to supporting their child with a diet and PA intervention. Parents were willing to change their own dietary behaviors to help their children successfully follow a weight loss intervention; however, no parent reported changing their own PA levels.

Conclusion: Future diet and PA studies should aim to reduce parental time commitment and increase importance of PA. © 2016 Elsevier Inc. All rights reserved.

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Childhood obesity is a global epidemic and has been termed “one of the most significant public health challenges of the 21st century.”¹ In the United States, approximately 31% of adolescents are overweight (BMI \geq 85th percentile) and 19% are obese (BMI \geq 95th percentile).² Adolescents with intellectual and developmental disorders (IDD) have significantly higher rates of obesity compared to typically developing adolescents.^{3–8} Rimmer et al⁷ reported that in adolescents with autism 42% are overweight and 25% are obese while in Down syndrome 55% of adolescents are overweight and 31% are obese. Moreover, obese adolescents are up to four times more likely

to become obese adults compared to their healthy weight peers, putting them at higher risk for developing additional comorbidities, such as hypertension, diabetes, and metabolic syndrome.^{9–12} However, there are currently no recommended weight management strategies for children and adolescents with IDD, and minimal research has been conducted to determine what the most effective weight loss and weight management strategies are for this population.^{13,14}

Parents play an important role in the lives of adolescents with IDD, especially in terms of weight control, as they perform the grocery shopping, meal planning and preparation, and have a role in the physical activity (PA) level of their child.¹⁵ In a recent literature review by Must et al¹⁴ and a recent systematic review by McGillivray et al,¹⁶ both found that successful obesity prevention and intervention strategies must influence both the diet and PA levels of the adolescents and children with IDD and the parents' attitudes and behaviors, the latter being rarely studied.

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Additionally, research has shown that when children and adolescents have parents that model healthy dietary behaviors, the risk of obesity decreases making it vital for programs to be tailored toward the parents as well as the child by incorporating feedback from the caregivers.^{17–19} Thus, the aims of this study are to better understand the parents' perspectives on the strategies and barriers for helping children and adolescents with IDD be successful in a weight management program and to identify how this information can be used to guide future approaches.

Methods

Overview

Participants were parents of children and adolescents (ages 11–18) enrolled in a diet and PA intervention for children and adolescents with IDD. Details on the diet and PA intervention have been previously published.²⁰ Briefly, a 2-month weight loss intervention was conducted where 20 children and adolescents were randomized into one of two diets: an enhanced Stoptlight Diet (eSLD) or a conventional diet (CD). The eSLD diet used portion-controlled meals (PCMs), which was comprised of two shakes and two entrées a day, and a color-coded stoptlight guide to help them choose healthy food items. The CD taught portion control and food group servings according to the USDA MyPlate guide.²¹ All children were given a tablet computer (Apple iPad 2TM) to track their dietary intake using the application Lose It! TM and their PA (steps) using the application FitbitTM. Parents were told to help their child or adolescent as needed in tracking diet and PA data.

The child or adolescent, along with a designated parent, attended weekly education lessons conducted over the FaceTimeTM application on the tablet computer. The iPadsTM and FitbitsTM were returned at the end of the study.

Parents were interviewed after completion of the program. Only one parent was interviewed per household. In households with more than one parent, the parent who was most involved with helping the adolescent follow the diet and PA program and who attended the weekly education sessions was selected for the interview. The University Institutional Review Board approved the study, and parents signed an informed consent form when enrolling their dependent in the diet and PA intervention. Parents could opt out of the interviews even if their dependent participated in the intervention.

Data collection

After the participant's child completed their final assessments for the intervention, face-to-face, semi-structured interviews were conducted using an interview guide developed by the study team (Table 1). An interviewer, who was not part of the intervention, conducted all interviews. The semi-structured interviews allowed parents to describe their family's experiences of following the prescribed diet and physical activity goals in depth and with richer detail. The qualitative interview process was intended to deepen our understanding of findings from the quantitative trial that examined the effectiveness of the intervention and to inform future research designs. Interviews began with parents filling out a demographic form. Parents were then asked semi-structured, open-ended questions tailored to their child's intervention group (eSLD or CD) addressing their

Table 1

Semi-structured interview guide for parents with adolescents following either an enhanced stoptlight diet (eSLD) or conventional diet (CD)

Main question	Follow-up question (if needed)	Probes
Tell me about your experience with the pre-packaged meals? (<i>eSLD only</i>)	What did you most like about the meals? (<i>eSLD only</i>) Tell about times when your child did not eat the meals? (<i>eSLD only</i>)	
Tell me about your experiencing using the stoptlight guide? (<i>eSLD Only</i>)	How well did your child understand the stoptlight diet? (<i>eSLD only</i>) What aspects of the guide would you change? (<i>eSLD only</i>)	
What were your favorite things about the diet? (<i>CD only</i>)	What aspects of the diet were hard for your or your child to follow? (<i>CD only</i>) What aspects did you enjoy? (<i>CD only</i>)	
What did you and your child like about the iPad?	Tell me about any problems you or your child had using lose it or istep log	Can you give me some examples?
What things did you or your child have trouble with?	What did you like about the Facetime meetings?	Was time an issue?
Now that you have completed the study how will you use this information in the future?	When you think about pre-packaged meals what is the likelihood your child will eat them in the future? (<i>eSLD only</i>) How will you use the lessons you learned about portion sizes? (<i>CD only</i>) How would you feel about continuing to track your child's dietary intake? How would you feel about continuing to track your child's physical activity?	
What do you feel we can improve?	Would you do this program again?	
How involved were you in helping your child follow their diet?	On a scale of 1–5, with 1 being never and 5 being always did you help your child enter food and physical activity into lose it? How did your physical activity level change as a result of your participations in this program? How did your diet change as a result of this program?	

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