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Caregivers' effect on weight management in adults with intellectual and developmental disabilities

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ABSTRACT

Introduction: Caregivers of adults with IDD often play a large role in the ability of adults with IDD to lose weight.

Objective: The purpose of this study was to determine to examine the effects of the caregivers' perceived burdens and self-efficacy and their relationship to an individual (family member or paid staff) on weight changes across a weight management intervention for adults with IDD.

Methods: Overweight/obese adults with mild to moderate IDD, along with assigned caregivers who served as their study partner, were randomized to an 18-month weight management intervention. The living environment and caregiver relationship were assessed at baseline. Caregivers completed questionnaires regarding perceived hassles, uplifts, and self-efficacy in helping the participant follow a weight management intervention.

Results: 147 adults with IDD (~57% women and ~16% minorities) were included in data analysis. After 18 months, there were no differences in weight loss between participants who had a family member as their study partner and those who had a paid assistant as their study partner ($-5.5 \pm 5.2\%$ vs. $-5.6 \pm 5.3\%$ $p = 0.16$). However, paid assistants reported more hassles with following the diet intervention at 6 months ($p < 0.05$). Participants who had a paid assistant as their study partner were more likely to have multiple study partners during the study, which was correlated with smaller weight loss.

Conclusion: While caregivers are important for weight management of adults with IDD, the caregiver's relationship to the participant does not affect weight change in an intervention.

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1. Introduction

Approximately 1–3% of the US population is diagnosed with an intellectual or developmental disability (IDD). IDD is defined as a disability, originating before the age of 10, characterized by significant limitations in both intellectual functioning ($IQ < 75$) and 2 or more adaptive behaviors.¹

As adults with IDD have left institutional care to live in group homes or supported living arrangements, they have adopted the physical activity^{2,3} and dietary characteristics^{4–6} of the general population and in turn have shown increased rates of overweight and obesity.^{7,8} The prevalence of obesity among individuals with IDD is approximately twice that in the general population, with up to 55% of adults with IDD considered obese ($BMI > 30 \text{ kg/m}^2$).^{9–11} This high rate of obesity combined with a lower level of fitness and poor diet quality has resulted in an increased risk of heart disease, diabetes, hypertension, and osteoporosis.^{3,12,13}

Adults with IDD live in a variety of different living environments: at home with parents or family, in group homes with live-in staff, and independently with occasional staff or parental support.¹⁴ While the living situations may vary, all have some type of

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caregiver support, typically either a family member or paid staff. The role of caregivers has been recognized as an important factor in meeting the needs of individuals with IDD.¹⁵ This is also true in providing support for weight management. While data is limited, previous studies have reported that support from family or paid caregivers may have a positive impact on weight loss for overweight and obese adults with IDD.^{16,17} Including caregivers in the realm of health promotion could provide an avenue for increasing physical activity and reducing energy intake.¹¹ Bergstrom et al.¹⁸ found that adults with IDD living in supported living homes had increases in physical activity after a weight management intervention.

It is unlikely that adults with IDD can effectively implement the components of a weight management intervention without social support from caregivers.¹⁹ However, caregivers experience many barriers to providing support for weight management to adults with IDD. Spanos et al.²⁰ identified staffing issues (e.g. constant turnover and lack of communication between staff members) and lack of caregiver knowledge on diet and physical activity as the two greatest barriers to providing successful weight management support. Matthews et al.²¹ completed a process evaluation of a walking intervention in adults with IDD and found that low morale for staff and increased demands in family caregivers were a few reasons for the lack of effectiveness in the trial. Thus, adults with IDD who live at home or in environments with one consistent care provider may have better support for weight management and therefore be more successful in a weight management intervention than those who live in homes with multiple staff.

Previous weight loss interventions in adults with IDD have generally involved small samples ($n < 25$) and been conducted over a relatively short time frame (8–12 weeks),²² thus there has not been the opportunity to examine the association between caregiver relationship and weight change in a long-term weight management intervention. Data from a recently completed 18-month weight management intervention in 149 adults with IDD afforded an opportunity to examine the effects of the caregivers' perceived burdens and self-efficacy and their relationship to an individual (family member or paid staff) on weight change.

2. Methods

2.1. Study overview

This was a secondary analysis of the data collected in an 18-month effectiveness study with adults with IDD that compared two intervention approaches for weight management. All study participants who completed 1 month of the intervention were included in the current investigation. A detailed description of the rationale, design, and methods of this study has been previously published.²³ In brief, 149 overweight/obese adults with mild to moderate IDD and their study partners were randomized to either an enhanced Stop Light Diet (eSLD)²⁴ or a Conventional calorie-restriction Diet (CD).²⁵ Following a 6-month weight loss period, both groups were encouraged to continue following their diet for 12 months at a level of energy intake estimated to result in weight maintenance.

The caregiver relationship (defined as family member or paid staff), living environment (independent living, group, or parent's home), and number of roommates were assessed at baseline using a demographic questionnaire completed by each participant's legal guardian (if applicable) or caregiver. The caregiver (staff) turnover and changes were tracked during the study, and a designated caregiver completed a nutrition hassles questionnaire at 0, 6, and 18 months of the study to determine their barriers, uplifts, and self-efficacy for helping the participant be successful in the

intervention. This study was approved by the Institutional Review Board at the University of Kansas.

2.2. Participants

The study was conducted between July 2011 and May 2014. All participants lived within ~50 miles of Lawrence, KS, United States of America, which includes the greater Kansas City Metropolitan. Participants were men and women, 18 years of age or older, with a diagnosis of mild to moderate IDD as determined by a Community Service Provider operating in Kansas under the auspices of a Community Developmental Disability Organization (CDDO). To be included in the study, participants had to reside in a supported living condition either at home or with no more than 1–4 residents and have a caregiver (parent or staff) who assisted with food shopping, meal planning, and meal preparation. Participants had to be overweight or obese ($BMI > 25 \text{ kg/m}^2$), able to walk, and have a clearance from their physician to participate. Potential participants also must have had the ability to communicate preferences (e.g., foods liked and disliked), wants (e.g., more to eat, drink), and needs (e.g., assistance with food preparation) through spoken language, sign language, or augmentative and alternative communication systems, such as voice output communication aides. Individuals were excluded if they had uncontrolled insulin dependent diabetes, hypertension, severe heart disease, cancer, or HIV. Individuals were also excluded if they had participated in physical activity and weight reduction programs within the past 6 months or were being treated for an eating disorder. If a female participant was or became pregnant, she was excluded/terminated from the study.

All participants were required to have a caregiver, defined as a parent/guardian whom the participant lived with or a direct care support staff who had primary responsibility for managing the house where the participant resided. The caregiver was referred to as the participant's "study partner." The study partner agreed to participate in each of the monthly meetings with the participant and to support the participant in following the intervention. Study partners were not asked to follow the diet or to increase their own physical activity. When study partners who were unable to complete their partner role (e.g., they changed jobs, they were no longer able to commit to attending the monthly meetings, participants moved out of their care, etc.), they were replaced. New caregivers were provided training that was identical to that received by the original caregiver.

2.3. Recruitment procedure

Participants were recruited through community and home visits. Written informed consent was obtained from either participants (self as guardian) or their legal guardian, and the caregiver.

2.4. Intervention overview

At baseline, participants and study partners attended a 90-min, at-home diet orientation session conducted by their assigned health educator, and subsequently participated in monthly at-home education sessions during the 18-month intervention with the same health educator. During a 6-month weight loss period, participants followed one of two different diet prescriptions, eSLD or CD. Following the weight loss period, both groups were encouraged to continue following their diet prescription for 12 months but at a level of energy intake designed to provide weight maintenance. Both groups were asked to wear a step counter and record steps walked with an eventual goal of 150 min per week.

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