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The Feasibility of Using Pedometers for Self-Report of Steps and Accelerometers for Measuring Physical Activity in Adults with Intellectual and Developmental Disabilities across an 18-month intervention

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Abstract

Background—Improving physical activity in adults with intellectual and developmental disabilities (IDD) is recommended to improve weight loss and general health. However, in order to determine the success of physical activity interventions, identification of feasible methods for assessment of physical activities is necessary. The purpose of this study is to assess the feasibility of adults with IDD to track daily steps and wear an accelerometer.

Methods—Overweight/obese adults with mild to moderate IDD followed a diet and physical activity program for 18 months. All participants were asked to wear a pedometer and track steps daily using a pedometer, and to provide accelerometer data for 7 days at baseline, 6, 12, and 18 months. Adherence to the pedometer protocol and plausibility of the number of recorded steps were assessed, and these measures along with average wear time of the accelerometer were recorded.

Results—Data were collected from 149 participants (36.5 ±12.2 years of age, 57% female). Participants recorded a step value on 81.5% of days across the 18-month study, with 40.9% of written days classified as plausible. When wearing the accelerometer, 26.8% of participants met the recommended 4-day/10-hr wear time criterion at baseline, and 22.6%, 24.8%, and 18.8% met the criterion at 6, 12, and 18 months, respectively.

Conclusion—Adults with IDD will adhere reasonably well to wearing a pedometer long-term, but may be unable to record the step data accurately. Furthermore, adults with IDD have poor compliance with accelerometer protocols, and future studies should determine if a shorter wear time protocol would produce valid data in this population.

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Keywords

Intellectual disabilities; self-monitoring; physical activity; accelerometer; pedometer

Introduction

The prevalence of obesity among individuals with intellectual and developmental disabilities (IDD) is approximately twice that in the general population, with up to 55% of adults with IDD considered obese (BMI >30 kg/m^2) (Rimmer et al., 1995, Rimmer and Wang, 2005, Harris et al., 2003, Yamaki, 2005). These high rates of obesity combined with lower levels of fitness and poor diet quality have resulted in an increased risk of heart disease, diabetes, hypertension, and osteoporosis (Carnethon et al., 2003, Neter et al., 2003, Woloshin and Schwartz, 2002, Grotto et al., 2003, Fontaine et al., 2003, National Heart, 1998, Evenson et al., 2003, Parker and Folsom, 2003, Hensrud, 2001, Beange et al., 1995, Draheim et al., 2002, U.S.Department of Health and Human Services Public Health Service, 2001).

Physical activity is considered an important strategy to promote weight loss because of its pivotal role in energy balance and the regulation of body weight through increased energy expenditure (Harris et al., 2015, Donnelly et al., 2009). However, adults with intellectual and developmental disabilities are less physically active than the general population (Melville et al., 2007a, Harris et al., 2015, Spanos et al., 2013, Rimmer et al., 1995, Rimmer et al., 2004). A review by Melville et al. (Melville et al., 2007b) found that only 8-16% of adults with IDD met criteria for a physically active lifestyle, compared with 20-37% of the general population.

While physical activity is considered important for weight management in the general population, there is limited literature to suggest increased physical activity will help to reduce weight in adults with IDD. A recent review by Harris et al. (Harris et al., 2015) indicates that physical activity interventions did not significantly change body weight or BMI in young adults with IDD. Possible explanations for the limited effects of physical activity interventions could be attributed to the ‘dose’ of physical activity prescribed in some interventions. However, the methodological approaches to collecting physical activity data have also been questioned (McGarty et al., 2014, Matthews et al., 2011, Phillips and Holland, 2011).

To date, assessment of physical activity in adults with IDD is mostly limited to self or proxy reports of physical activity (Phillips and Holland, 2011). Self-report, typically using a pedometer, offers advantages to the participant as it provides accountability and self-efficacy. Basic pedometers have shown low rates of error and acceptable validity in their ability to count daily steps in the general (Park et al., 2014) and IDD (Stanish, 2004) populations. However, the ability of adults with IDD to remember to wear a pedometer, record their steps, and the plausibility of step tracking recorded has been questioned (Matthews et al., 2011). While a number of studies in adults with IDD have used pedometers, they have only assessed physical activity levels over a short period of time via pedometer data (Hilgenkamp et al., 2012a, Pitchford and Yun, 2011, Temple and Stanish, 2009, Agiovlasitis et al., 2012, Hilgenkamp et al., 2012b, Stanish, 2004). For example,

Stanish (Stanish, 2004) measured the walking activity of individuals with mild IDD across 7 days, and determined that adults with IDD without Downs syndrome walked approximately 11,800 steps/day compared with 5,600–8,800 steps/day for adults with DS. However, the feasibility of the adult to wear the pedometer daily long-term and accurately track their steps, as necessary in lifestyle interventions, has not been reported.

Accelerometers are more sophisticated motion sensors compared to pedometers, and are considered valid and reliable for physical activity assessment in typically developing adults (Troiano et al., 2008). In adult populations, a person is required to wear the accelerometer for 4 days with a minimum of 10 hours of daily wear time to be considered valid (Troiano et al., 2008). There have been a limited number of studies using accelerometers in adults with IDD (Frey, 2004, Temple, 2009, Melville et al., 2011, Spanos et al., 2015, Phillips and Holland, 2011), and none have validated the use of accelerometers in this population. Due to complexities of accelerometer measurement (Ward et al., 2005) (e.g. remembering to wear the belt, having the belt touch your skin or rub against your clothes, keeping the belt on all day), the feasibility of accelerometer use in adults with IDD has been questioned (McGarty et al., 2014).

The aims of this study are to determine the feasibility of using pedometers for self-monitoring of physical activity and accelerometers for outcomes assessments of physical activity in adults with IDD across an 18-month diet and physical activity intervention in 149 adults with IDD. To determine if pedometers are feasible tools for daily self-report of physical activity (steps), the plausibility of daily step tracking via pedometer use was assessed for 18-months. To determine if accelerometers are a feasible outcomes measure for physical activity in research interventions, the average accelerometer wear time at 4 times points (baseline, 6, 12, and 18 months) was assessed across the same 18-month study.

Methods

Overview

Data was obtained from a randomised controlled trial examining a diet and physical activity intervention in community dwelling adults with IDD. A detailed description of the rationale, design and methods of that study (Donnelly et al., 2013) as well as the main outcomes (Ptomey et al., 2017) have been previously published. Briefly between June 2011 and May 2015, 149 overweight/obese adults, living in the greater Kansas City Metropolitan in the United States, with mild to moderate IDD and their caregivers were randomised to an 18-month effectiveness trial with 6 months weight loss and 12 months weight maintenance to compare two diets: an enhanced stop light diet and a conventional diet for weight management. Both diet groups were given the same physical activity recommendation of 150 minutes of physical activity a week. Participants and their caregivers were assigned a health educator and met with that health educator once a month to review compliance to the intervention, answer questions about the diets or physical activity program, gain support, and receive nutrition and physical activity education instruction. All participants were asked to wear a pedometer and record daily steps for 18 months, and wear an accelerometer belt for 7 consecutive days at four time points across the study (baseline, 6, 12, and 18 months).

Participants

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 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 care giver (i.e. parent, staff) who assisted with food shopping, meal planning, and meal preparation. Participants had to be overweight or obese (BMI > 25 kg/m^2), able to walk, and have clearance from their physician to participate. Participants were required to have 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 PA 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 and referred to an appropriate agency.

Caregivers

All participants were required to have a caregiver. A caregiver was defined as a parent/guardian who the person lives with, or a direct care support staff who has primary responsibility for managing the house where the individual resides. The caregiver agreed to attend a training session with the participant, participate in each of the meetings with the participant, and help the participant track their physical activity. Caregivers were not asked to follow the diet or increase physical activity. Caregivers who were unable to complete the trial were replaced. New caregivers were provided training that was identical to that received by the original caregiver.

Recruitment procedures/randomization

An information brochure that described the project was mailed/emailed to case managers and service providers in the recruitment area. Potential participants were contacted by a member of the investigative team who is familiar with the sensitive issues regarding recruitment of individuals with IDD. Home visits were scheduled to verify eligibility and answer any remaining questions. University approved consent forms were reviewed with the participant (self as guardian) or their legal guardian and their caregiver. Written informed consent was obtained from either the participant (self as guardian) or their legal guardian and their caregiver. Randomization was completed after written consent and written physician clearance were obtained.

Participant and Caregiver Training

Prior to initiating the intervention, participants and their caregiver completed a 60-90 min. orientation session with their health educator designed to teach the basic principles of the intervention, as well as describe the procedures and requirements for self-monitoring. The

physical activity recommendations were explained to both intervention groups, and instructions on how to wear and use the pedometer were provided.

Daily Physical Activity Tracking

All participants were instructed to engage in at least 30 minutes per day of moderate intensity physical activity at least 5 days per week with a target of 150 minutes per week. To help achieve this goal, participants were asked to gradually accumulate ~30 minutes of walking per day. Pedometers (Omron HJ-320, Lake Forest, IL) were provided to all participants as both a motivational tool and to self-monitor physical activity. If the participant lost or broke the pedometer, they were given a replacement.

The Omron HJ-320 is a commercial grade pedometer that automatically resets itself at the end of the day and has a 7-day memory. It has shown low rates of error when worn on the waist in the general population (Park et al., 2014). Spring level pedometers, like the Omron HJ-320, have shown high intraclass correlations (ICC > 0.95) for when used by adults with mild IDD on a 400 m walking track(Stanish, 2004).

Participants were instructed to wear the pedometer daily for the 18-month study, and track daily steps on data recording cards provided by the study team. Caregivers were instructed to help remind the participant to wear the pedometer daily and record their daily steps. However, caregivers were asked not to write down the steps for the participant.

Monthly Meetings

Health educators conducted monthly 45-60 min. home visit meetings with participants and their caregivers across the 18-month trial. Each participant's body weight was assessed and weekly self-monitoring tracking sheets were reviewed to provide feedback regarding progress with weight loss and compliance with the study protocol. Health educators answered questions about the diet and physical activity recommendations, and taught problem solving/relapse prevention strategies to assist participants in maintaining compliance with the intervention, such as reviewing safe places to go on walks and how to fit activity into their daily schedule. During the monthly meetings, if the health educator noticed a participant was not wearing the pedometer or recording their daily steps, they would provide recommendations to both the participant and the caregiver on how to remember to wear the pedometer and track steps each day. If a participant discontinued participation in the study, step data collection was discontinued.

Feasibility of Step-Data

All step data was classified as missing or non-missing. Missing step data was defined as any day during the intervention period where a weekly data-recording card was turned-in but daily step values were left blank. Plausibility of the non-missing step values was assessed as ≥1,703 steps per day or ≤24,369 steps per day, which correspond to the minimum and maximum extreme step values reported in adults with IDD living in community settings (Peterson et al., 2008), and is similar to the extreme step values used in the general population (i.e. < 1000 and >25,000 steps/day) (Tudor-Locke et al., 2011).

Accelerometer Data

To obtain more in depth physical activity data, participants were asked to wear an ActiGraph GT1X portable accelerometer belt (ActiGraph LLC, Pensacola, FL) for 7 consecutive days at baseline, 6, 12, and 18 months. Participants and caregivers were given written instructions to wear the belt over the non-dominant hip, only taking it off to shower, swim, or sleep. Accelerometer data was collected in 1-min epochs. We assessed how many days (1-7 days) participants wore the belt for 6 hours, 8 hours, and 10 hours.

Statistical Analysis

Sample demographics and all outcome measures were summarised by descriptive statistics —means and standard deviations for continuous variables and frequencies and percentages for categorical variables. Availability and feasibility of step data were reported using frequencies and percentages of missing/non-missing records and valid step records. In addition, independent-sample *t*-test was conducted to compare the average percent of missing records and feasible records between those classified with mild IDD and those with moderate IDD. Accelerometer data were downloaded using ActiGraph software and processed using a custom SAS program developed by our group. Non-wear time was identified as ≥60 consecutive minutes with 0 cts·min^{-1}, with allowance for 1–2 minutes of accelerometer counts between 0 and 100 (Troiano et al., 2008). Individuals meeting accelerometer wear time criteria were reported using frequencies and percentages. Participants were only included in the analysis if they were active in the study during that outcome period. Statistical significance was determined at 0.05 alpha level, and all analyses were performed using SAS Software, version 9.3 (SAS Institute Inc., Cary, NC).

Results

One hundred and forty-nine individuals were enrolled in the intervention and completed baseline assessments. One hundred and forty-seven individuals completed at least one month of the study, and 124, 113, and 101 participants completed 6, 12, and 18 months of the intervention, respectively. Full baseline demographic data for the 149 participants are presented in Table 1. This sample comprised ~57% women and ~16% minorities, with the mean age of ~36 years and BMI of ~37 kg/m^2.

Daily Step Tracking

Daily step tracking was available from the 147 participants who completed at least 1 month of the intervention. Participants turned in ~58% of weekly-data cards; thus, there was a combined total of 7,243 days of physical activity data from the 147 participants. Participants wrote a step value down on 81.5% of days (5,905 days), and had a missing value on 18.5% of days. Of the 5,905 days that participants recorded a non-missing value, only 40.9% of days were found to be plausible, as 56% of days were recorded as <1,703 (implausibly low) and 3.2% of days as >24,369 (implausibly high). There were no significant differences in missing records (p=0.74) or feasibility (p=0.38) between those classified with mild IDD and those with moderate IDD. There were no significant differences in missing records (p=0.14) or feasibility (p=0.45) between those classified with family members as caregivers and those with paid staff.

Accelerometry

At baseline, 149 participants were given the accelerometer to wear for 7 days; however, no participant wore the accelerometer for greater than 4 days. Only 26.8% of participants met the 4-day/10-hr minimum criterion. This trend was seen as the study progressed with only 22.6%, 24.8%, and 18.8% meeting this criterion at 6, 12, and 18 months, respectively. By shortening the minimum required wear time from 4-day/10hr to 3 day/8-hr, only 66.% of participants met the criterion at baseline, and 46.8%, 40.7% and 29.7% at 6, 12, and 18 months, respectively. Table 2 shows the number of participants at baseline, 6, 12, and 18 months that wore the accelerometer for a length of time meeting the 10-hrs, 8-hrs, or 6-hrs criterion.

Discussion

The feasibility and validity of self-reported physical activity and physical activity measured by accelerometer has been questioned in adults with IDD. This study examined the feasibility of adults with IDD to track their daily steps and wear an accelerometer.

In general, the ability of adults with IDD to self-report data was poor, with weekly-data only available for 58% of study weeks. However, looking at the available data, it appears adults with IDD were able to wear a pedometer daily and record their steps 81.5% of the time. While, the pedometer adherence in this study is appears better than adherence in typically developing adults, where average adherence is 52.5%-76% (Talbot et al., 2003, Schneider et al., 2011, Bickmore et al., 2013), the validity of the recorded data remains in question, as 60% of the recorded data was not considered plausible. Participants may have had trouble recording the correct number on their data sheet, only wore the pedometer part of the day, or recorded higher numbers than they achieved in order to please the investigators. When accounting for missing days and days not considered feasible, only 33% of total collected step data was available and feasible. Furthermore, when accounting for tracking sheets that were never turned in, feasible step data was found in only 19% of study days.

These results demonstrate that adults with IDD will wear activity devices on a daily basis for at least 18 months, but also showed that their ability to accurately record the data and turn it in may be limited. The use of wearable technology that automatically records daily physical activity and steps, such as FitBit, Garmin, and Jawbone physical activity monitors may be improve the ability to obtain physical activity data in this population. These devices only require the participant to wear the device, as they automatically send the data to an online cloud server, thus reducing the burden of manually recording steps and physical activity. While no studies have used these activity monitors in adults with IDD, a pilot trial in adolescents with IDD used FitBits to monitor physical activity across 12-weeks, and successfully obtained Fitbit data 72% of study days (Ptomey et al., 2015). Previous research in typically developing adults, has found that wearable technology is highly acceptable. A study by Cadmus-Bertram et al. (Cadmus-Bertram et al., 2015a) found that 95% of participants wore a FitBit monitor 10-hrs/day for 112 days. Furthermore, participants who wore the Fitbit had greater increases in physical activity than those who wore a basic pedometer (Cadmus-Bertram et al., 2015b). Future studies are needed to determine the feasibility of using wearable technology, such as FitBits, in adults with IDD. Another

alternative device is the Omron HJ 720 Pedometer, which has a 42-day memory that can be downloaded for data collection and has shown acceptable validity in adults with IDD (Pitchford and Yun, 2010).

Data obtained by accelerometer was also limited, with only 27% providing the 4-day/10-hr criterion typically used in adults (Troiano et al., 2008). Previous research in adults with IDD have used shorter wear time criterions. For example, Melville et al. (Melville et al., 2011) used a 3-day/6-hr wear time criterion, and obtained data for 45 out of 54 (83%) participants at baseline and 33 (61%) at a 6-month follow up period. Spanos et al. (Spanos et al., 2015) also used the 3-day/6-hr protocol and obtained data for 18 of the 28 (64%) participants. Spanos et al. reported issues with the use of accelerometer that included: participants forgetting to wear the accelerometer, removing them when in day-centers, or caregivers forgetting to remind them to wear it. For the current study, the 3-day/6-hr criterion would have provided data for 72.5% of participants at baseline and 66.9%, 54.8%, and 42.6% at 6, 12, and 18 months, respectively. While our study and others have been able to obtain accelerometer data from 61%-83% of participants using a shorter wear time criterion, the validity of these shorter wear times has not been established.

Data from this study and others suggest that adults with IDD have poor compliance with waist-worn accelerometer protocols. Due to many individuals removing the belt during the day, the wrist worn accelerometer may be a more feasible option; however, intensity cut-points are not yet available for wrist worn accelerometer data.

This study benefits from a large sample size and 18-month collection period. However, it is limited as all participants were from a convenience sample of overweight and obese adults with IDD, and thus, the results are not generalizable to healthy weight adults with IDD. Another limitation is that, while similar spring loaded pedometers have been validated in adults with IDD, the Omron HJ-320 pedometer has only been validated in typically developing adults. Also, data regarding the number and types of reminders that participants needed to wear the pedometer and collect their data was not collected. Finally, this study only assessed the feasibility to wear the pedometer, and did not validate the step-reported daily step values or the plausibility cut-off points. One previous study (Kim and Yun, 2009) compared pedometer values from to accelerometer values to examine intra-individual variability and inter-instrument variability when measuring physical activity in youth with IDD. However, as the accelerometer has not been validated in this population, we did not feel that was a suitable option for this study.

Improving physical activity in adults with IDD is important to both weight loss and general health. In order to determine the success of physical activity interventions, feasible and accurate assessment of physical activities are necessary. This study found that while adults with IDD will adhere to a daily pedometer protocol, they have trouble with recording accurate step data and turning the data in. Future studies should consider the use of physical activity trackers that do not require self-report. Furthermore, adults with IDD have poor compliance to accelerometer protocols. Future studies need to determine the validity of accelerometers in this population and determine if shorter-wear time criterion would still produce valid data.

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Table 1

Sample Characteristic of Adults with IDD participating in an 18month weight management intervention.

	Total Sample (n=149)
Age [a]	36.5 ±12.2
Gender [b]	
Male	64 (43%)
Female	85 (57%)
Race [b]	
White	125 (83.9%)
African American	19 (12.7%)
Asian	2 (1.3%)
Native American or Alaska Native	1 (0.7%)
Two or more Races	2 (1.3%)
Ethnicity [b]	
Hispanic or Latino	4 (2.7%)
Education Level [b]	
Less than 9th grade	5 (3.4%)
9th-12 grade	21 (14.1%)
High school or GED	94 (63.1%)
Post graduate classes	29 (19.5%)
Diagnosis [b]	
Down Syndrome	26 (17.4%)
Autism	20 (13.4%)
Unknown/Not Specified	103 (68.1%)
Severity of IDD	
Mild	75 (50.3%)
Moderate	74 (49.7%)
Caregiver Relationship	
Family Member	40 (26.8%)
Paid Staff	109 (73.2%)
Anthropometric Data [a]	
Weight (kg)	98.4±24.3
Height (cm)	163.0± 11.9
BMI (kg/m^2)	36.9± 7.81

[a] Reported in mean ± SD

[b] Reported in N (%)

Table 2

Accelerometer wear time for adults with IDD

	10-hr criterion			8-hr criterion			6-hr criterion		
	N	***n***	***%***	***N***	***n***	***%***	***N***	***n***	***%***
Baseline									
1-day criterion	149	120	80.5%	149	126	84.6%	149	128	85.9%
2-day criterion	149	108	72.5%	149	114	76.5%	149	118	79.2%
3-day criterion	149	75	50.3%	149	99	66.4%	149	108	72.5%
4-day criterion	149	40	26.8%	149	62	41.6%	149	77	51.7%
5-day criterion	149	0	0.0%	149	0	0.0%	149	0	0.0%
6-day criterion	149	0	0.0%	149	0	0.0%	149	0	0.0%
7-day criterion	149	0	0.0%	149	0	0.0%	149	0	0.0%
Month 6									
1-day criterion	124	90	72.6%	124	97	78.2%	124	104	83.9%
2-day criterion	124	81	65.3%	124	86	69.4%	124	92	74.2%
3-day criterion	124	58	46.8%	124	76	61.3%	124	83	66.9%
4-day criterion	124	28	22.6%	124	45	36.3%	124	58	46.8%
5-day criterion	124	1	0.8%	124	1	0.8%	124	1	0.8%
6-day criterion	124	1	0.8%	124	1	0.8%	124	1	0.8%
7-day criterion	124	0	0.0%	124	0	0.0%	124	1	0.8%
Month 12									
1-day criterion	113	77	68.1%	113	81	71.7%	113	84	74.3%
2-day criterion	113	60	53.1%	113	71	62.8%	113	75	66.4%
3-day criterion	113	46	40.7%	113	55	48.7%	113	62	54.9%
4-day criterion	113	28	24.8%	113	34	30.1%	113	40	35.4%
5-day criterion	113	0	0.0%	113	0	0.0%	113	0	0.0%
6-day criterion	113	0	0.0%	113	0	0.0%	113	0	0.0%
7-day criterion	113	0	0.0%	113	0	0.0%	113	0	0.0%
Month 18									
1-day criterion	101	63	62.4%	101	68	67.3%	101	73	72.3%
2-day criterion	101	42	41.6%	101	49	48.5%	101	57	56.4%

	10-hr criterion			8-hr criterion			6-hr criterion		
	N	***n***	**%**	***N***	***n***	**%**	***N***	***n***	**%**
3-day criterion	101	30	29.7%	101	36	35.6%	101	43	42.6%
4-day criterion	101	20	19.8%	101	24	23.8%	101	30	29.7%
5-day criterion	101	0	0.0%	101	0	0.0%	101	0	0.0%
6-day criterion	101	0	0.0%	101	0	0.0%	101	0	0.0%
7-day criterion	101	0	0.0%	101	0	0.0%	101	0	0.0%