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Remote Exercise for Adults with Down Syndrome

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Abstract

Purpose—Adults with Down syndrome are less physically active than their typically developed peers. The purpose of this study was to assess the feasibility of delivering moderate-to- vigorous exercise sessions, led by a trained health educator using real-time video conferencing, to groups of young adults with Down syndrome in their homes.

Methods—Participants were randomized to 30-minute group exercise sessions either 1 or 2 times a week delivered on an iPad mini tablet computer using the Zoom video conferencing application, and were asked to attend individual support/education sessions once a week using FaceTime® on the iPad, for 12 weeks. Minutes of MVPA during all group sessions were assessed using a Fitbit Charge HR activity/heart rate monitor. Participants were also asked to complete weekly homework assignments involving MVPA.

Results—Twenty-seven participants (n = 14,1 session·wk^{-1}, n =13, 2 sessions·wk^{-1}), mean age 27.9 ± 7.1 yrs., ~ 41% female, enrolled in and completed the 12-wk. intervention. Attendance at group exercise and individual support/education sessions did not differ significantly between those randomized to 1 (exercise sessions =89.9 ± 8.8%, support/education sessions = 81.2 ±18.7%) or 2 sessions·wk^{-1} (exercise sessions = 88.8 ± 7.7%; p=0.79, support/education sessions= 86.0 ± 20.9%; p=0.87). Participants averaged 27.7 ± 5.7 mins·session^{-1} of MVPA with no significant difference between the 1 (26.6 ± 3.0 mins·session^{-1}) and 2 session·wk^{-1} groups (28.8 ± 7.7 mins·session^{-1}, p=0.16). The completion rate for homework assignments did not differ significantly between the 1 (21.4 ± 26.3%) and 2 session·wk^{-1} groups (37.7 ± 21.7%, p=0.28).

Conclusion—Exercise delivered by group video conferencing may be a feasible and potentially effective approach for increasing MVPA in adults with Down syndrome.

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Conflict of Interest

No authors report any conflicts of interest, and the results of this study do not constitute endorsement of ACSM.

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Keywords

Down syndrome; exercise; MVAP; technology; remote delivery

INTRODUCTION

Participation in moderate-to-vigorous physical activity (MVPA) in the approximately 250,000 individuals in the United States diagnosed with Down syndrome (1) is much lower than their typically developed peers. It is estimated that only 9% of adults with intellectual and developmental disabilities (IDD) (2), including Down Syndrome, compared with ~52% of typically developed adults (3) achieve 150 mins·wk^{-1}. of MVPA as recommend by the Physical Activity Guidelines for Americans(4). Reports by Stanish et al. (5) and Temple et al (6) indicated that 28% of adults with IDD "never" or "rarely" engaged in MVPA. Baseline MVPA, assessed by portable accelerometer in a sample of 150 adults with IDD who participated in an 18-month weight management trial recently competed by our group, was only 15 mins·day^{-1} (7). Increased MVPA in individuals with IDD has been associated with decreased body weight (8), improved cardiovascular fitness (9, 10), and improved muscular strength and endurance (11, 12). Preliminary evidence suggests increased MVPA may also be associated with improved cognitive function in adults with Down syndrome (13–15), which may be particularly important considering that approximately 70% of adults with Down syndrome, whose lifespan is 55 to 60 years, will develop Alzheimer's disease, with symptoms beginning in the third decade of life (16).

Adults with Down syndrome face several barriers which increase the complexity of developing interventions to increase MVPA for this group. The barriers which make the initiation and maintenance of MVPA difficult for typically developed adults may be amplified in adults with Down syndrome as a result of cognitive impairment, which may result in difficulty with planning, delaying rewards, taking initiative and understanding abstract information(17). Lack of social support and an understanding of the potential benefits of increased MVPA, lack of physical skills and trained professionals for assistance, and the lack of affordable/accessible transportation to facilities to participate in MVPA represent significant barriers for adults with Down syndrome (18, 19).

The majority of interventions that have evaluated strategies to improve initiation and maintenance of MVPA in individuals with Down Syndrome have focused on adolescents rather than adults (20–22). For example, Stanish and Temple (22) reported successful attendance (~90%) at a 15-week peer-supported exercise intervention (2 days·wk^{-1}, 60 minutes), for adolescents with IDD (n=20, age ~ 18 years). Participants were provided a complementary membership to the YMCA where the intervention was conducted. However, only 3 participants used the facility (1–4 times) on non-program days. The limited research on increasing MVPA in adults with IDD is short duration, includes all intellectual disabilities and not specifically those with Down syndrome, and has been unsuccessful in increasing short-term (≤ 12 weeks) MVPA (7, 23–25). For example, Melville et al.(23) randomized 102 adults with IDD to a 2-week consultation-led walking invention or non-intervention control. Participants in the intervention group received three consultations with

a walking advisor and were encouraged to set walking goals and monitor their daily step count with a pedometer. At 12 weeks there were no significant between group differences in steps (69.5 steps·day^{-1}, p =0.90) or the percentage of time·day^{-1} spent in MVPA (1.5%, p = 0.5) both assessed by portable accelerometer. The limited available information, and the potential benefits of increased MVPA, highlight the need to develop and evaluate intervention strategies to promote increased MVPA in adults with Down syndrome.

Interventions delivered using real-time video conferencing have been used to improve health and modify behaviors in typically developing adults (26–28). Other technologies such as computers and tablets have been used successfully to teach academic subjects and to improve social and daily life skills in individuals with IDD across the age spectrum (29). A recent study conducted by our group in adults with IDD, indicated that 90% of adults with IDD had access to wireless internet, either in their homes or at their day centers (30). Thus, interventions to increase MVPA, delivered via video conferencing to groups of adults with Down syndrome in their homes, represents a potentially effective approach for increasing MVPA in this group. This approach requires no travel commitment from care providers or parents, since the need for transportation to a YMCA or community center is eliminated, and offers the potential for peer support and socialization, which may be important for initiation and maintenance of MVPA. However, the feasibility of at-home, group-based exercise sessions, delivered using video conferencing to young adults with Down syndrome is unknown and was the focus of this pilot trial. For this study feasibility was defined as session attendance ≥ 70% and overall program attrition <20%.

METHODS

Study design-Overview

Adults with Down syndrome were computer randomized with equal allocation to at- home, group exercise sessions delivered by a trained health educator using video conferencing (Zoom Inc., San Jose, CA) on an iPad mini tablet computer (Apple Inc., Cupertino, CA) either 1 or 2 days·week^{-1} over 12-weeks. Randomization to 1 or 2 days·week^{-1} allowed an assessment of the impact of session frequency on program attendance and attrition. Duration and intensity of MVPA during group sessions was assessed using Fitbit Charge HR (Fitbit Inc. San Francisco, CA) wireless activity tracker/heart rate monitor. Participants also met with the health educator weekly via FaceTime® to receive support and education designed to assist with intervention compliance. Participants were asked to complete a “homework” assignment involving physical activity each week. The study protocol was approved by the Human Subjects Committee at the University of Kansas Medical Center.

Participants

Men and women, with a diagnosis of Down syndrome verified by their primary care physician, were recruited through local community programs serving adults with IDD, and with print and web advertisements in the target area, i.e. greater Kansas City, KS/MO. All recruitment materials included investigator contact information, i.e., toll-free phone and email. Questions from interested participants/guardians were addressed and initial eligibility screening was completed via phone or email. Home visits were scheduled with potential

participants and their legal guardian (if applicable) to explain the project, answer questions, determine eligibility, and obtain written consent or legal guardian consent and participant assent. The following inclusion/exclusion criteria were applied: Inclusion: 1) Age 18–35 yrs. Older participants were not included to reduce the probability of undiagnosed dementia or Alzheimer's disease, as working with individuals with dementia or Alzheimer's disease which is outside of the scope of staff capabilities, 2) Functional ability sufficient to understand directions and to communicate through spoken language, 3) Reside in a supported living condition either at home or with no more than a total of four residents, and have a caregiver, i.e., parent, staff who agrees to serve as a study partner. 3) Wireless Internet access in the home. 4) Ability to participate in MVPA verified by physician consent. Participant exclusion criteria included: 1) Currently pregnant, or planning on becoming pregnant during the study. 2) Participation in a regular exercise program, defined as greater than 500 kcal/wk. of planned activity as estimated by questionnaire (31) completed by the participant with caregiver assistance.

Study partner

Most adults with Down syndrome live with a caregiver, e.g., a family member, guardian, or paid staff who assists with daily tasks such as food shopping/preparation, transportation, and paying bills. Caregivers play a potentially pivotal role in promoting MVPA for adults with Down syndrome, e.g., assisting with scheduling and participation in appropriate physical activities, and providing transportation to sites to engage in MVPA (32). Thus, each participant was required to have a parent/guardian or residential support staff, who served as a study partner for the duration of the intervention. However, the role of the study partner was intentionally minimal and included attendance at the study orientation and weekly support/education sessions, and reminding participants of upcoming group exercise sessions. Study partners were not asked participate in exercise sessions or to assist participants with weekly homework assignments.

Intervention

Orientation—Prior to initiating the intervention, the health educator conducted one ~60 minute home visit with both participants and their study partner. During this session the health educator oriented participants to the use of intervention equipment that was provided as part of the trial, i.e., iPad mini, Fitbit Charge HR, resistance bands, mini cones, throwing scarves, and HDMI adaptors which allowed the group videoconference sessions to be displayed on a larger TV screen. Participants were also oriented to the Zoom software which included instruction on how to use the camera, control the sound and how to ensure that all other participants in the exercise sessions were visible on the screen. Basic aerobic exercises and exercises using the resistance bands were demonstrated, and time was allotted for questions and troubleshooting. Downloading of non-study related applications or internet browsing was restricted on all iPads. Participants returned the iPad, and the HDMI adaptor to the investigators at the completion of the study. Participants were allowed to keep the Fitbit and received $25 for completing baseline testing and completing the 12-week intervention ($50 total) as an incentive.

Exercise Sessions—Sessions of ~ 30 minutes duration, were delivered via video conferencing either one or two times per week over 12 weeks to groups of 5–8 participants, each in their own home. Groups were formed based on mutual time availability, and were generally conducted in the late afternoon or early evening. Exercise sessions were led by a health educator who was a specialist in adapted physical education and experienced in working with adults with Down syndrome. Participants, who could all be seen simultaneously on the video display, were encouraged to interact with other participants and the health educator. To promote participant interaction, the health educator asked participants to select songs to accompany the session, and to lead parts of the warm-up and cool-down activities. A sample video clip from a group exercise session is included in the supplemental digital content (see Video, SDC1, Clip of a group exercise session, 03:48, 31.1MB).

Sessions consisted of a warm-up (~ 5 min.), MVPA, i.e., 3–6 METs, (~20 min.), and a cool down (~5 min.). MVPA included aerobic activities such as walking/jogging in place, jogging to music, dancing, and strength based exercises such as vertical jumps, bicep curls, and squats. Exercise sessions followed daily scripts designed to reflect weekly themes such as “bounce, jump, and stretch”, “throw, go, and roll”, and “dance, dance, dance”. No session was the same throughout the intervention. Intensity of the exercise sessions, monitored by Fitbit (described below) increased progressively from ~ 20% to ≥ 50% of estimated maximal heart rate across the first 6 weeks of the intervention, then remained at ≥ 50% over weeks 7 to 12. Maximal heart was estimated as 210 minus 0.56 * (age in yrs.) minus 31 as suggested by Fernhall et al. (33) for use in individuals with Down syndrome. The 1 and 2 session·wk^{-1} groups were conducted separately, but were led by the same health educator.

Individual Support/Education—Participants and their study partner were asked to attend weekly 20-minute support/education sessions with their health educator conducted using FaceTime® on the iPad. The health educator covered a weekly topic such as the importance of exercise for health, the selection of appropriate exercise clothing and footwear, importance of maintaining adequate hydration etc. At the end of each session participants were asked to set a personal exercise goal for the next week, such as creating a dance routine, learning how to do push-ups, or trying a physical activity they had never done before.

Homework—All participants were asked to complete a weekly homework assignment designed to assist participants in meeting the weekly personal exercise goal they set during the individual support sessions. Participants were asked to make short videos of themselves completing their assignments using the iPad camera. Videos were automatically uploaded to Apple iCloud. The health educator logged into each participant’s iCloud account to verify completion of homework assignments.

Assessments

Demographic information, i.e., age, race/ethnicity, sex, for both participants and study partners was collected only at baseline. Attendance at group exercise and individual support/education sessions, minutes of MVPA during group sessions, and homework completion

were measured across the 12-week study. Physical measures, i.e., height, weight, and waist circumference, were obtained by study staff during a home visit.

Attendance—Attendance at both group exercise and individual support/education sessions was recorded by the health educator. Group exercise session attendance was defined as being logged in to the video conference and remaining on the screen for the entire 30-minute session. Attendance at individual support/education sessions was defined as answering the FaceTime® call, and being present on screen for the entire session.

Minutes of MVPA—Participants were asked to wear a Fitbit Charge HR on their non-dominant wrist during all group exercise sessions. While the Fitbit has not been validated in individuals with Down syndrome, acceptable validity and test-retest reliability of Fitbits for the quantification of MVPA in both laboratory and free-living conditions has been demonstrated in the general population (34, 35). For example, Alharbi et al (34) recently reported daily MVPA estimated by the Fitbit Flex and an ActiGraph GT3 accelerometer differed by only 10 minutes·day^{-1}, i.e. <1%. The Fitbit estimates MVPA based on both motion and heart rate data using a proprietary algorithm.

The health educator asked participants to start and stop the Fitbit at the beginning and end of each exercise session. To ensure participants were exercising at the prescribed intensity participants were randomly asked to verbally report their heart rate or show their Fitbit heart rate output to the health educator two to three times during each exercise session. Participants exercising below their prescribed heart rate were encouraged increase exercise intensity. Fitbit data was automatically uploaded to the Fitbit application on the iPad. Following the completion of each exercise session the health educator logged in to the participant's Fitbit account and recorded the minutes of MVPA.

Semi-structured interviews—At the completion of the trial, in-person, semi-structured interviews were conducted with each participant and their study partner to gather information on the overall ease and enjoyment of the program, and information regarding specific program components such as the value of homework assignments and the use of the Fitibt. Interviews which required ~20 min to complete, followed a written script which included probing follow-up questions for participants who provided uninformative initial responses.

Height, weight, waist circumference—Standing height was assessed to the nearest cm with a portable stadiometer (Model #IP0955, Invicta Plastics Limited, Leicester, UK). Weight was assessed to the nearest 0.1 kg with a calibrated scale (Model #PS6600, Belfour, Saukville, WI). BMI was calculated as weight (kg) divided by height (m^2). Waist circumference was assessed using the procedures described by Lohman et al. (36). Three measurements were obtained with the outcome recorded as the average of the closest 2 measures. Participants wore shorts and a t-shirt for all assessments.

Statistical Analysis

Sample demographics and all additional measures were summarized by descriptive statistics, i.e., means and standard deviations for continuous variables and frequencies and percentages

for categorical variables. Percentage of exercise and support/educations sessions attended and homework assignments completed as well as average exercise session MVPA were calculated for each participant over the 12-week intervention. Proc GLM was used to conduct t-tests to assess between group differences in exercise and support/education session attendance, exercise session MVPA, and completion of homework assignments adjusting for sex, age, education level, race/ethnicity, and BMI. Additionally, Proc GLM was used to conduct t-tests for between group differences in weight, BMI, and waist circumference adjusting for sex, age, education level, and race/ethnicity.

Statistical significance was determined at alpha= 0.05. All analyses were performed using SAS Software, version 9.4 (SAS Institute Inc., Cary, NC).

RESULTS

Participants/Attrition (Table 1)

Twenty-seven young adults with Down syndrome, mean age 27.9 years, 40.7% females, and 10.1% minorities enrolled in the trial. There was no attrition as all participants remained engaged over the entire 12-week intervention.

Session attendance and homework

Average attendance was 89.5% and 83.5% for the group exercise and individual support/education sessions, respectively. There were no significant differences in exercise session attendance between those randomized to 1 (89.9 ± 8.8%) or 2 sessions·week^{-1} (88.8 ± 7.7%; $F_{df = (1,16)} = 0.07$, p=0.790). Attendance at individual support/education sessions did not differ significantly between groups (1 session·week^{-1} = 81.2 ± 18.7%; 2 sessions·week^{-1} = 86.0 ± 20.9%; $F_{df = (1,16)} = 0.03$, p=0.866). The completion rate for homework assignments did not differ significantly between the 1 (21.4 ± 26.3%) and 2 session·wk^{-1} groups (37.7 ± 21.7%, $F_{df = (1,16)} = 1.23$, p=0.284).

Group session MVPA

Participants averaged 27.7 ± 5.7 min·session^{-1} of MVPA with no significant difference between the 1 (26.6 ± 3.0 min·session^{-1}) and 2 session·week^{-1} groups (28.8 ± 7.7 min·session^{-1}, $F_{df=(1,16)} = 2.19$, p=0.158, total MVPA =57.7 ± 15.3 min·week^{-1}).

Semi-structured interviews

All 27 participants completed the interviews and all indicated that group video activity sessions were enjoyable and easy to fit into their schedule. Twenty-six participants (96%) indicated that they would continue attending the group video and support/education sessions if the intervention were to continue beyond 12 weeks. Nineteen participants (71%) reported that they enjoyed completing the homework assignments. However, several participants commented, that without reminders from their study partner, they often forgot to document the homework by video recording, as requested. Twenty-five participants (93%) reported that they enjoyed using the Fitbit and indicated that tracking activity was a good motivator. Responses to interview items did not differ between the 1 and 2 session·week^{-1} groups.

DISCUSSION

Adults with Down syndrome have low levels of MVPA and face numerous barriers that increase the complexity of delivering effective interventions for increasing MVPA in this underserved group. Results of this pilot trial suggest that a combination of home-based group exercise sessions, delivered by a trained health educator using commercially available video conferencing software, and brief weekly support/education sessions delivered via FaceTime® may provide a feasible alternative to traditional on-site approaches for increasing MVPA in adults with Down syndrome. All participants completed the 12 week intervention, attended ~89% of group exercise and ~84% of support/education sessions, and averaged 28 minutes of MVPA during each session. Attendance at both exercise and support/education sessions was similar in the 1 and 2 session·week^{-1} groups which suggests that at least 2 group exercise sessions·week^{-1} is feasible in adults with DS.

Reports indicate the PA levels of adults with IDD including Down Syndrome are low (2, 4). Our group recently found that at baseline adults with IDD only obtained 15 minutes of MVPA a day (105 minutes·week^{-1}). We are not aware of any previous trials designed specifically to evaluate strategies for the delivery of MVPA to adults with Down syndrome. Results from a short-term trial (15 weeks) in a small sample of adolescents with IDD (n=20, age ~18yrs.), not specifically Down syndrome, indicated 85% completion of aerobic exercise sessions conducted at a community YMCA (22). While successful over the short-term in adolescents, the long-term sustainability of attendance at an on-site program for adults with Down syndrome is questionable. Additional many agencies that serve individuals with Down syndrome cannot afford individual gym memberships for each client. Our results suggest that over the short-term, i.e., 12 weeks, the group video approach scheduled for 2 days·week^{-1} can provide ~ 56 minutes·week^{-1} of MVPA for adults with Down syndrome. An additional group exercise session each week, if sustainable, has the potential to provide ~ 84 minutes of weekly MVPA, or 56% of weekly total MVPA recommended to achieve health benefits (4). The delivery of exercise sessions by group video eliminates the need for transportation, requires minimal involvement by care providers, and offers the potential for social interaction and support. However, there are some cost associated with this delivery system, e.g., tablet computers, internet, Fitbits.

Additional adequately powered trials will be required to evaluate the long-term sustainability of group video approach, i.e. ≥ 6 months, the impact of group exercise sessions on total daily MVPA and sedentary time, the optimal frequency of group sessions, and to compare the effectiveness of the group video and on-site approaches for effectiveness and participant and provider costs. If the results of these trials are positive, community agencies providing services to adults to adults with Down syndrome would have a viable low-cost option for promoting increased MVPA among individuals that they serve. This technology-based approach may also allow agencies to provide MVPA to individuals with Down syndrome living in areas that do not have access to gyms or other community programs as well as those who lack the resources to attend in-person exercise programs.

In addition to attending group exercise and individual support/education sessions, participants were asked to complete a weekly homework assignment that required additional

physical activity. The rate of completion of these assignment, which was based on video recordings of the activities made by participants, was quite low, i.e., ~30%. Comments from semi-structured interviews suggest that the rate of completion of homework assignments may be underestimated as a result of participants failing to record their activity. Nevertheless, additional strategies to improve the compliance the physical activity outside the scheduled group exercise sessions need to be developed and evaluated. Study partners were not asked to help the participant with the homework assignment, the use of the study partner to help remind and film the participant may be one strategy to increase homework compliance in the future.

The results of this study suggest that video conferencing may be a feasible approach for improving MVPA in adults with DS. However, this study is limited by a small sample (n= 27) of young adults with DS, who were incentivized to participate in a short-term (12 week), non-randomized trial, and thus should be interpreted cautiously. The use of the Fitbit, which has not been validated specifically for this population, lack of assessment of non- exercise session MVPA, and lack of documentation of study partner attendance are additional limitations.

In summary, results of this pilot trial suggest that video conferencing is a potentially feasible approach for the delivery of PA to young adults with DS, and that multiple sessions per week may be feasible, as well as beneficial, for increasing total weekly MVPA. Adequately powered trials to further evaluate the feasibility of video conferencing for the delivery of PA over longer time frames (e.g. ≥ 6 months), with increased group exercise sessions during the week, to assess changes in weekly MVPA and memory are warranted. If shown to be sustainable and effective in the long term, the group video conference would be a viable low-cost option for use by community agencies interested in promoting increased MVAP in young adults with Down syndrome that they serve.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Baseline characteristics of adults with Down syndrome participating in a exercise intervention

	1 session per week		2 sessions per week	
	N	**Mean+SD/%**	***N***	**Mean+SD/%**
Age (yr)	14	29.9 ± 7.5	13	25.8 ± 6.7
Weight (kg)	14	80.1 ± 20.1	13	73.9 ± 15.6
Height (cm)	14	59.4 ± 3.2	13	60.5 ± 4.1
Waist Circumference (cm)	14	93.7 ± 13.6	13	89.6 ± 10.2
BMI ($kg \cdot m^{-2}$)	14	35.4 ± 9.7	13	31.4 ± 6.8
Number of Support Staff	14	3.1 ± 1.8	13	3.0 ± 2.0
Education level (%)				
9th–12th	3	21.4	1	7.7
High School/GED	10	71.4	9	69.2
Some College	1	7.1	3	23.1
Ethnicity (%)				
Not Hispanic/Latino	13	92.9	12	92.3
Hispanic/Latino	1	7.1	1	7.7
Race (%)				
American Indian	1	7.1	0	0.0
Black	1	7.1	0	0.0
White	12	85.7	12	92.3
Mixed Race	0	0.0	1	7.7
Sex (%)				
Male	8	57.1	8	61.5
Female	6	42.9	5	38.5