

## BRIEF REPORT

# Brief report: Caregiver perceived physical activity preferences of adults with Down syndrome

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## Abstract

**Background:** Adults with Down syndrome commonly have low levels of physical activity and face social barriers to engaging in physical activity, including boredom and companionship concerns. Adults with Down syndrome are at increased risk for several co-occurring medical conditions known to benefit from physical activity, including obesity and dementia.

**Method:** This study surveyed 140 caregivers of adults with Down syndrome to determine the physical activity preferences of their adult with Down syndrome.

**Results:** Dancing was the most frequently caregiver-reported physical activity preference for adults with Down syndrome, followed by walking and active video gaming. Rowing, using an elliptical machine, and jogging were the least preferred activities. Most caregivers reported that their adult with Down syndrome has a companion available for physical activity.

**Conclusion:** Promoting dance in adults with Down syndrome, a caregiver-reported preferred form of physical activity, may help improve physical activity levels and decrease sedentary behaviours in this population.

## KEYWORDS

dance, Down syndrome, physical activity

## 1 | BACKGROUND

Down syndrome is a genetic condition resulting from extra material from chromosome 21 (Bull, 2020). Individuals with Down syndrome tend to have low daily physical activity (PA) levels, high levels of sedentary behaviour, and seldom meet the national physical activity recommendations for adults (Agiovlasis et al., 2020; Oreskovic et al., 2020). Adults with Down syndrome have low physical fitness levels and are at increased risk for several co-occurring medical conditions, including obesity and dementia, which are conditions that are known to benefit from increased PA (Beck et al., 2021; Bull, 2020; Pitetti et al., 2013; Ptomey et al., 2018). Reducing obesity can also help address many other highly prevalent resulting conditions in Down syndrome, including obstructive sleep apnea and arthritis. To address these activity-related medical conditions, ideally, adults with

Down syndrome would increase PA levels and decrease sedentary behaviour.

Improving PA levels in adults with Down syndrome requires careful consideration of the barriers and facilitators to PA for this population. Previously reported barriers to PA in adults with Down syndrome include boredom, lack of accessible programs, companionship concerns and lack of support from others, and accessible transportation (Heller et al., 2003; Love & Agiovlasis, 2016; Mahy et al., 2010). Caregivers—family, guardians, and paid helpers who look after and assist individuals with Down syndrome—play an important role in encouraging, accessing, and facilitating PA in adults with Down syndrome (Guerra et al., 2019; Mihaila et al., 2017). Until more research is done to validate survey measures from people with Down syndrome, who have varying levels of intellectual disability and communication skills, caregiver-proxy reports have provided

important insights into this population (Chung, Donelan, et al., 2021; Chung, Sarathy, et al., 2021; Ilacqua et al., 2020). A better understanding of caregiver's perceptions of PA preferences, including activity categories and timing preferences, of adults with Down syndrome is needed. Also essential is an accounting of the availability of caregivers to facilitate participation, aid in designing PA programs, and ensure that increased PA is achievable and sustainable while sedentary behaviours are minimised. Given the well-documented low PA and high sedentary behaviour levels, the known health benefits of PA, and the important role of caregivers in facilitating and promoting PA in adults with Down syndrome, this study sought to assess how caregivers perceive the PA preferences of the adults with Down syndrome they care for.

## 2 | METHODS

### 2.1 | Participants

Caregivers of individuals 18 years and older with Down syndrome were recruited through the Massachusetts General Hospital (MGH) Down Syndrome Program website, Facebook, and Twitter pages in February of 2019. The survey was open to all caregivers of adults with Down syndrome; adults with Down syndrome did not have to be followed at MGH for study eligibility. Caregivers interested in taking the anonymous survey were directed via an internet link to an IRB exempt online questionnaire using Harvard University's Research Electronic Data Capture (REDCap) database (Harris et al., 2009).

### 2.2 | Survey

We designed a brief survey assessing the PA preferences of adults with Down syndrome. Survey questions were based on previously

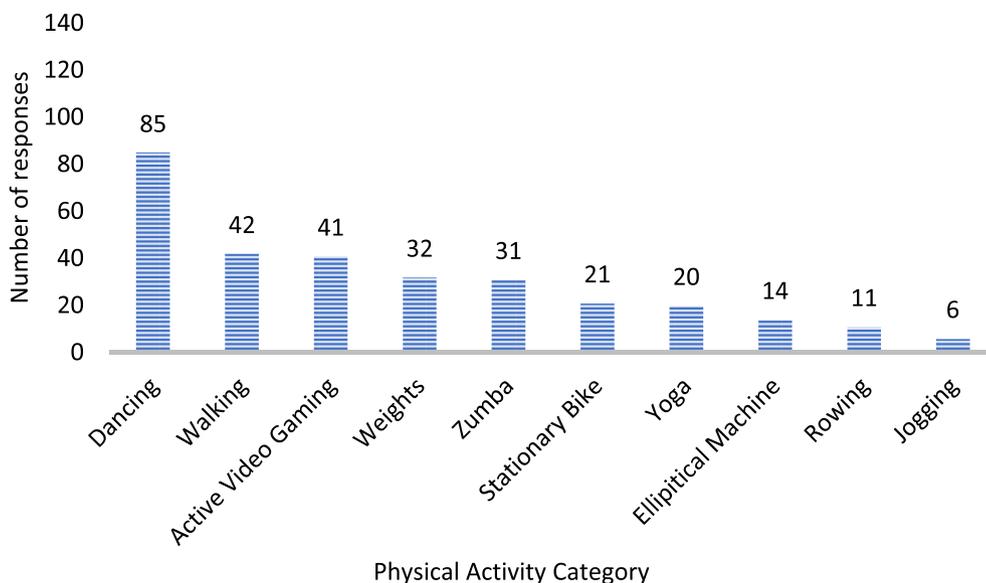
reported factors identified as important in PA among individuals with Down syndrome (Love & Agiovlasitis, 2016). The survey assessed for preferred PA type, PA variation preferences, and for the presence of a PA companion (see Supplementary Materials). Physical activity types included physical activities that could be done with or without a companion, but did not require organisation, large or expensive equipment or infrastructure, or other participants, such as team and organised sports or aquatics. *Physical activity preferences* were assessed with two multiple checkbox questions: (1) 'If we asked [name] to do an activity every day, what type of activity do you think [name] would prefer to do?' with respondents allowed to choose more than one answer, and (2) 'Which 2 activities do you think [name] would most like to do?' Answer options were 'walking', 'jogging', 'dancing', 'yoga', 'Zumba', 'active video gaming', 'stationary bicycle', 'rowing machine', 'elliptical machine', and 'resistance training/weights'.

Physical activity variation preferences were assessed by asking caregivers to select one of the following two options: 'If we asked [name] to do an activity every day, would [name] prefer to (1) do the same activity each time or (2) do different activities?'

To assess companion availability, caregivers were asked: 'We know that most individuals with Down syndrome prefer to do physical activities with other people. Is there anyone in [name]'s household who could do a daily PA program with [name]? This could be a family member, a friend, or a staff member'. Answer option was Yes/No.

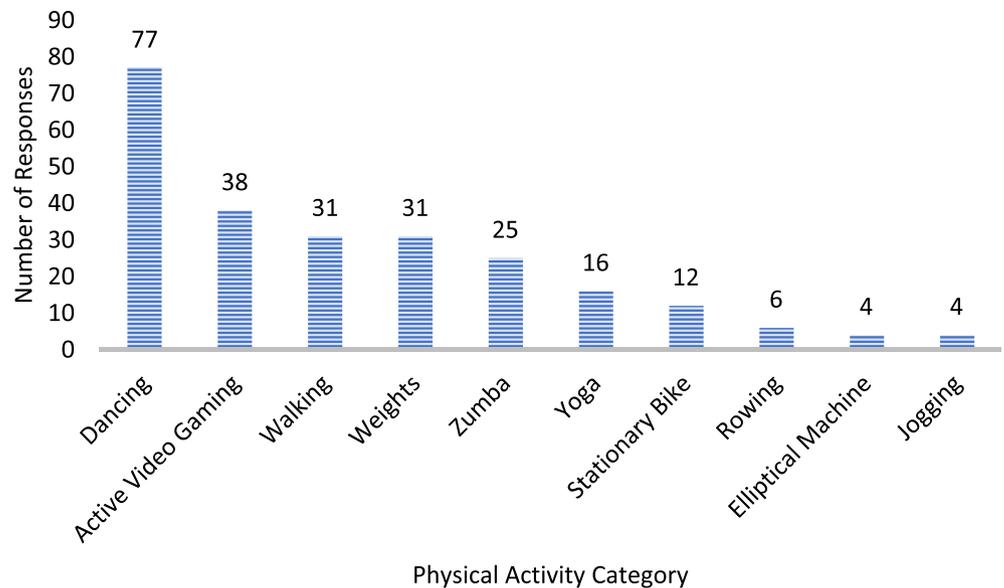
### 2.3 | Data analysis

Summary statistics on frequencies of responses were calculated for each survey question and used to report caregiver answers. Total frequency exceeded 140 as multiple responses were collected for each question. We used chi-square tests to compare PA preferences based on companion availability.



**FIGURE 1** Caregiver reported physical activity preferences for adults with Down syndrome

**FIGURE 2** Top two caregiver reported physical activity preferences for adults with Down syndrome



### 3 | RESULTS

One hundred and forty-one caregivers started the survey, with 140 completed. Sixteen (11%) survey respondents lived outside the United States. When asked to name the top PA type that the adult with Down syndrome would most like to do, caregivers most frequently reported ‘dancing’ as the preferred PA type (61%), followed by ‘walking’ (30%) and ‘active video gaming’ (29%), with other responses reported by less than a third of caregivers (Figure 1). Jogging (4%), rowing (8%), and elliptical machine (10%) were the three least selected PA preferences for adults with Down syndrome. When asked to limit their options to the top two PA types that adults with Down syndrome would most like to do, caregivers reported ‘dancing’ as the most preferred (77%), followed by ‘active video gaming’ (38%), ‘walking’ (31%), ‘resistance training/weights’ (31%), ‘Zumba’ (25%), ‘yoga’ (16%) and ‘stationary bicycling’ (12%), with ‘rowing’, ‘jogging’ and ‘elliptical machine’ remaining the least desirable options chosen by fewer than 5% of responders (Figure 2). A large majority (90%) of caregivers reported that someone from within the household would be available to engage in PA with their individual with Down syndrome. Slightly over half of caregivers (58%) reported that adults with Down syndrome would prefer to alternate different PA types day-to-day, while the rest felt adults with Down syndrome would want to do the same activity each time. Dancing was the preferred PA type reported for both individuals with and without an available companion. Walking and Zumba were the second most frequently reported physical activities preferences for individuals with and without a companion, respectively ( $\chi^2 = 50.5, p < .00001$ ).

### 4 | DISCUSSION

According to caregivers, dancing is the preferred form of PA in adults with Down syndrome, and most adults with Down syndrome have a

companion available for PA. The results have implications for promoting PA, overcoming known barriers to PA, and reducing sedentary behaviour in adults with Down syndrome.

Dancing is a safe, achievable and effective form of health-enhancing PA across a range of health outcomes (Fong Yan et al., 2018). Boredom is a known barrier to PA whereas enjoyment has been identified as an important contributor to positive PA experience among adults with Down syndrome (Heller et al., 2003; Love & Agiovlasitis, 2016). Dancing may represent a fun and engaging form of PA that has the potential to overcome boredom and facilitate enjoyment. Dancing can also be done anywhere, including at home, and may therefore also overcome transportation and companionship barriers. In addition to boredom and transportation, individuals with Down syndrome have unique physiologic and metabolic barriers that inhibit PA and promote sedentary behaviours including low motor tone, poor coordination, decreased peak oxygen consumption levels, and a reduced capacity to deliver oxygen to organs during PA (Bertapelli et al., 2020; Fernhall et al., 2013; Hilgenkamp et al., 2018). Dancing is a versatile form of PA that can be performed at one’s own pace and can be adapted for individuals with motor or cognitive disabilities, thereby holding the potential to overcome physiologic and social barriers to PA in individuals with Down syndrome. Dancing can also be done alone or with others, and indeed we found that dancing was the favoured PA reported for individuals with and without a companion. Our findings add to recent work focusing on dance as a potential approach to increasing PA in adults with Down syndrome, including a recent pilot study supporting the use of adaptive dance to improve motor abilities and PA engagement (McGuire et al., 2019).

Active video gaming and walking were identified by caregivers as two other popular forms of PA, at nearly identical rates. Interestingly, active video gaming and brisk walking have been found to have similar energy expenditure requirements (Çakir-Atabek et al., 2020), and physical activities at this intensity level may represent an optimal energy expenditure range for adults with Down syndrome.

In a recent randomised controlled trial, active video gaming was shown to increase physical and functional fitness in adults with Down syndrome (Perrot et al., 2021). Walking interventions in adults with Down syndrome have been shown to improve a variety of outcomes, including cognitive function, strength, and balance (Carmeli et al., 2002; Chen et al., 2014; Ptomey et al., 2018). Promoting physical activities such as active video gaming and walking could provide important opportunities to reduce sedentary time, increase PA, and improve health outcomes including co-occurring medical conditions in this high-risk population. Dance video games, such as *Dance Dance Revolution* or *Just Dance*, which combine dancing and active video gaming, two preferred activities in adults with Down syndrome, have been shown to increase PA and reduce sedentary time in several high-risk adult populations (Kloos et al., 2013; Maloney et al., 2008; Natbony et al., 2013; Smith et al., 2011); these activities may also effectively facilitate PA in adults with Down syndrome. Importantly, dancing, active video gaming, and walking yield a relatively high energy expenditure and may improve weight control in adults with Down syndrome who are commonly overweight or obese (USDHHS, 2005).

Resistance training was another caregiver-reported preferred form of physical activity. Recent research has shown that progressive resistance training programs can be adopted by individuals with Down syndrome and may be beneficial for increasing upper and lower limb strength as well as overall daily PA levels (Shields et al., 2008; Shields & Taylor, 2010; Shields et al., 2013). Resistance training often involves a partner, and with most survey respondents indicating exercise partner availability for their individual with Down syndrome, resistance training may represent another feasible option for increasing PA.

Caregivers reported rowing, jogging, and elliptical machine exercises as the least preferred forms of activity. Adults with Down syndrome may not prefer these forms of PA because they involve large muscle groups and are more likely to be intense especially relative to aerobic fitness, which is very low in adults with Down syndrome (Fernhall et al., 2013). Alternatively, caregivers may not perceive or expect individuals with Down syndrome to prefer or be capable of engaging in such activities. Rowing and elliptical aerobic exercises may be challenging for individuals with low motor coordination and short stature. These activities also require specialised equipment that is typically available in fitness centers; however, past research indicates that individuals with Down syndrome face many barriers in accessing fitness centers (Heller et al., 2003). Jogging, a PA that is done at a relatively constant pace throughout the duration of the activity and without an objective or goal, may not be perceived as a sufficiently fun form of PA by adults with Down syndrome. The low preference for these activities may also reflect negative past experiences with poorly designed programs. Engaging in such activities may yield positive experiences if adults with Down syndrome perform them under the guidance of knowledgeable PA professionals (Pitetti et al., 2013).

Nearly all adults with Down syndrome had a reported exercise partner available. Having support from others facilitates PA in adults with Down syndrome and may help overcome transportation barriers to PA that adults with Down syndrome experience (Heller et al., 2003; Mahy et al., 2010). Having an exercise partner may also provide motivation and make an activity more fun; to this end, past research has shown that social interaction is an important facet of enjoyment of PA among adults with Down syndrome (Love & Agiovlasitis, 2016). We found some evidence for variations in PA preference by companion availability, with walking being the second most preferred activity among individuals with exercise partners, compared to Zumba for those without partners. Enjoyment and interest could also be promoted by alternating PA types between days as over half of caregivers reported. However, nearly half of caregivers indicated that performing the same activity is preferred, consistent with past research indicating that routine and familiarity facilitates PA in adults with Down syndrome (Mahy et al., 2010). There may be variation between adults with Down syndrome on this issue, suggesting that assessing PA preferences on an individual basis may be needed.

The limitations of this study included obtaining information on preferences from caregivers, an indirect source of information. While our survey included a broad range of multiple-choice options for PA, there may have been other preferred activities that were not included. Our sample was not population-based, and as data collected were anonymous, we were unable to assess for variations by age, race/ethnicity, geography, culture, gender and intellectual abilities. In addition, our questions are not validated and may yield potential bias. Despite these limitations, it is clear from these data that dancing is a preferred form of PA in individuals with Down syndrome. Given the low levels of PA in this population, the known health-related risks associated with low PA, and the increased prevalence of health conditions in individuals with Down syndrome that are impacted by PA and weight control, finding ways to harness information on PA preferences, such as designing dancing interventions, and recommending dancing as a form of PA may be of great importance.

## 5 | CONCLUSION

Dancing was the preferred form of caregiver-reported PA in adults with Down syndrome. Most adults with Down syndrome have an available PA companion. Dancing may offer an approach to promote PA and decrease sedentary behaviours in this population.

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## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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