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## Research in Autism Spectrum Disorders

journal homepage: www.elsevier.com/locate/rasd



## Parents' perspectives of physical activity participation among Canadian adolescents with Autism Spectrum Disorder



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### ARTICLE INFO

Number of reviews completed is 2 Keywords: Autism spectrum disorder (ASD) Physical activity Health Co-morbid conditions Qualitative research Physiotherapy

#### ABSTRACT

*Background:* Despite the numerous health and social benefits of regular physical activity participation, adolescents with autism spectrum disorder (ASD) are less likely to be active compared to their age-related peers. Yet, little is known why they are predominantly inactive, with a paucity of research that has examined how socio-behavioural mechanisms influence their participation. With no previous research in Canada, and very limited research in this area, this study examined parents' perspectives and experiences of physical activity participation.

*Method:* Ten in-depth interviews were conducted with parents of adolescents with ASD. Interview data was analyzed thematically.

*Results*: Parents prioritized behavioural/communication interventions over physical activity throughout their adolescent's life. This prioritization was most pronounced during childhood, and the lack of participation during their formative years shaped physical activity interests in adolescence. Second, parents also described experiencing systemic challenges when accessing physical activity programs, including a lack of awareness of ASD among service providers, funding challenges, and limited/few program options. The lack of PA individualization and competing commitments contributed to tremendous strain on families. Third, the findings suggest early guidance is needed to help parents balance family life, schooling, and therapies with PA.

*Conclusion:* Findings suggest that biological and socio-behavioural mechanisms functioned concurrently to influence physical activity participation. A family-centred, multidisciplinary collaborative approach that includes health care practitioners such as physical therapists can potentially be used to facilitate physical activity participation. Efforts educating community service providers about ASD are also needed in an effort to increase participation.

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https://doi.org/10.1016/j.rasd.2018.01.007

Received 19 August 2017; Received in revised form 16 January 2018; Accepted 20 January 2018 Available online 02 February 2018 1750-9467/ © 2018 Elsevier Ltd. All rights reserved.

#### 1. Introduction

Emerging research consistently suggests that regular physical activity (PA) participation reduces the risks of cardiovascular disease, increases cognitive function, exhibits positive effects on markers of mental health (Carson, Ridgers, & Howard, 2013; Lee & Hopkins, 2013), and facilitates overall positive health outcomes (Carson, Rinaldi, & Torrance, 2014). Additionally, adolescents (aged 11-21 years) who are physically active are more likely to develop positive peer relationships (Utay & Utay, 2005, learn new skills and movement patterns (Lee & Hopkins, 2013), and in turn develop habits to guide PA in adulthood (Singh, Uijtdewilligen, & Twisk, 2012). For individuals with autism spectrum disorder (ASD), PA may have a number of additional physical, psychosocial, and cognitive benefits that can help address some of the challenges associated with ASD (Celiberti, Bobo, Kelly, Harris, & Handleman, 1997; Hallal, Victora, Azevedo, & Wells, 2006; Janssen & LeBlanc, 2010; Lang et al., 2010; Petrus et al., 2008). Research suggests that PA can help create schedules and routines, improve motor control, and increase self-efficacy for individuals with ASD (Lang et al., 2010; Sowa & Meulenbroek, 2012). Engagement in PA can also increase aerobic capacity, strength, and overall fitness of individuals with ASD, which enhances physical health, and psychological well-being (Lochbaum & Crews, 2003). In relation to mental health, reduced stress and anxiety have been noted following exercise, where decreased salivary cortisol levels have been observed (Hillier, Murphy, & Ferrara, 2011). Specific to the needs of individuals with ASD, PA can improve social and communication skills, increase self-esteem, improve cognition, and decrease self-stimulating/self-injurious behaviour (Sorensen & Zarrett, 2014). Aerobic exercise in particular has shown to be effective in reducing maladaptive and stereotypic behaviours among adults with ASD (Elliott, Dobbin, Rose, & Soper, 1994).

Despite the numerous health and social benefits of regular PA (Lalonde, MacNeill, Eversole, Ragotzy, & Poling, 2014), adolescents with ASD are less likely to be physically active compared with their age-related peers (Pan et al., 2016). Not only are adolescents with ASD predominantly physically inactive during childhood (Pan & Frey, 2006), they typically become even less active during adolescence both at school and in the community (Bandini et al., 2012). It is perhaps not surprising that many adolescents with ASD do not meet recommended physical activity guidelines (Criado, Sharp, & McCracken, 2017). With declining PA during adolescence (MacDonald, Esposito, & Ulrich, 2011) side effects of psychotropic medication treating core ASD symptoms often resulting in weight gain (Anagnostou, Aman, & Handen, 2016; Anagnostou et al., 2014), and high levels of participation in sedentary activities (Must et al., 2013), physical inactivity positions adolescents with ASD at higher risk to potentially acquire complex acute and chronic health conditions (Pitetti, Rendoff, Grover, & Beets, 2007). As such adolescents are at higher risk of developing obesity, cardiovascular disease, diabetes, musculoskeletal disorders, anxiety, and depression (Bomjin, 2004). These chronic health conditions can negatively impact adolescents' social, physical, and mental health, as well as increase their chances of having obesity as adults (Hill, Zuckerman, & Fombonne, 2015) which can confer poor health (Hadjiyannakis et al., 2016). Given the potential for PA to mitigate some of these acute and chronic conditions, there is a need to examine how to enhance PA in this population.

To date, much of the research examining PA among adolescents with ASD has focused on addressing its characteristic impairments (MacDonald et al., 2011; White, Oswald, Ollendick, & Scahill, 2009) with a focus on somato-motor performance (balance, speed, gait, postural stability and joint flexibility) and bio-physical behaviours (inattention/hyperactivity). Although this research is very valuable, it is important to also understand the complex mediators of PA beyond the level of individual physical impairments. Yet, little is known how socio-behavioural mechanisms such as social, personal, structural, attitudinal and familial mechanisms influence PA. With much of the research quantifying the rates, patterns, and habits of PA, exploring socio-behavioural mechanisms which influence PA has the potential to provide novel insights regarding physical inactivity among adolescents with ASD. Not only is there a paucity of research examining how socio-behavioural mechanisms influence PA, there is no previous Canadian research that has examined parents' perspectives. Given that parents are central figures in promoting and providing PA opportunities for their children (Baranowski, 1997; Sallis, Prochaska, & Taylor, 2000), knowledge regarding parents' values, experiences, and PA preferences could be used to inform, and better serve the PA needs of adolescents with ASD.

Acknowledging the gaps in research outlined above, the purpose of this qualitative study was to explore how social, personal, systemic, attitudinal and familial mechanisms (hereafter socio-behavioural mechanisms) influence PA among Canadian adolescents with ASD. Drawing on interviews, the study explored parents' perspectives regarding their adolescent child's PA experiences to examine the socio-behavioural mechanisms which enhance, shape, or curtail PA participation.

#### 2. Method

#### 2.1. Study design

We used a descriptive qualitative methodology and semi-structured interviews to explore parents' experiences, perceptions, and beliefs regarding their adolescent's PA participation. Descriptive qualitative research is a form of interpretive research (Sandelowski, 2000) allowing researchers to stay close to their data to interpret events and life experiences of a group of individuals (Abramsky et al., 2017). As such, descriptive research is often exploratory in nature elucidating insights into how individuals experience the social world, and can be a valuable resource in areas that have been have under-researched, and are devoid of a robust empirical, conceptual, or substantive basis. Given the limited research in this area and the exploratory nature of our study, a descriptive qualitative methodology was ideally suited to our inquiry. This methodological approach in turn allowed for an in-depth examination of the multidimensional mechanisms which enhance, shape, and curtail PA participation. Research ethics approval was obtained from the University of Toronto Health Science Research Ethics Board.

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