

Contents lists available at ScienceDirect

Research in Developmental Disabilities

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



"I'm not in this alone" the perspective of parents mediating a physical activity intervention for their children with autism spectrum disorder



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ARTICLE INFO

Keywords:
Autism
Physical activity
Exercise
Telehealth
Parents
Facebook

ABSTRACT

Background and aims: Web-based, parent-mediated interventions have shown to be beneficial for children with autism spectrum disorder (ASD) in a variety of domains. We aimed to examine how parents of children with ASD perceive mediating a physical activity intervention delivered via a private Facebook group.

Methods: Thirteen families participated in a four-week trial of Project CHASE. Inductive thematic analysis of semi-structured interviews and interactions within the Facebook group were conducted to elicit the perspective of the parents.

Outcomes and results: Thematic analysis resulted in three themes emerging: (1) 'Remembering to Act' encompassed the participants' perspectives of Project CHASE as being an intervention that reminded them of the importance of physical activity, and served as a prompt for them to take action; (2) 'A sharing community' included the subthemes of 'sharing success and struggles' and 'sharing ideas'; and, (3) 'Taking control: possibilities and problems' encapsulates the dichotomy between participants who spoke of embracing and rising to the challenge of taking control, with the parents who spoke of the need for more support, direction, and guidance.

Conclusion and implication: The current study suggests parent-mediated, web-based interventions may have the potential for improving the effectiveness of physical activity interventions for children with ASD.

What this paper adds?

- The current study highlights a method for developing a web-based, parent-mediated intervention, based on social cognitive theory, for increasing physical activity among children with ASD.
- Parents perceived the intervention to be particularly useful as a source of motivation, a reminder for them to take action, and as a source of social support.
- This study highlights the challenges parents may experience when mediated a physical activity intervention; although some
 parents spoke of embracing and rising to the challenge of taking control of their child's physical activity, others spoke of the need
 for more support, direction, and guidance from experts.

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1. Introduction

1.1. Physical activity among youth with autism

Physical activity offers youth with autism spectrum disorder (ASD) an array of benefits. A recent meta-analysis (Healy, Nacario, Braithwaite, & Hopper, 2018) demonstrated a moderate to large positive effect for youth with ASD exposed to interventions targeting the development of manipulative skills, locomotor skills, skill-related fitness, social functioning, and muscular strength and endurance. Yet youth with ASD remain less active than their typically developing (TD) peers (Corvey, Menear, Preskitt, Goldfarb, & Menachemi, 2016; Healy, Haegele, Grenier, & Garcia, 2017; McCoy, Jakicic, & Gibbs, 2016; Pan, Tsai, Chu, & Hsieh, 2011; Pan, Tsai, Hsieh et al., 2011) and tend to fail to meet current Centers for Disease Control and Prevention (CDC) guidelines of acquiring one hour of moderate to vigorous physical activity per day (Memari et al., 2015; Pan, Tsai, Chu et al., 2011; Pan, Tsai, Hsieh et al., 2011; Pan & Frey, 2006). The proposed reasons for this lack of adequate physical activity are numerous. Individual and family level barriers reported by parents (Must, Phillips, Curtin, & Bandini, 2015) and children with ASD (Healy, Msetfi, & Gallagher, 2013, 2017; Obrusnikova & Cavalier, 2011) include the need for supervision of the child, parental time constraints, behavioral problems, motor skills deficits, and a preference for sedentary behaviors. Social barriers have been proposed also, including a lack of experts to include children with ASD in physical activity programs (Must et al., 2015) and a lack of peer partners (Obrusnikova & Miccinello, 2012).

1.2. Limited scalability and sustainability of current interventions

The research base on physical activity interventions for youth with ASD demonstrates an array of exercise modalities to be beneficial for children with ASD. Some examples include exergaming (Dickinson & Place, 2014), aquatic programs (Fragala-Pinkham, Haley, & O'Neil, 2008; Fragala-Pinkham, Haley, & O'Neil, 2011; Pan, 2011), horse-riding programs (Wuang, Wang, Huang, & Su, 2010), and treadmill walking (Pitetti, Rendoff, Grover, & Beets, 2007). One important challenge remaining is how to translate these findings to effectively implement these interventions on a larger scale, and achieve sustained effects on behavior. Considering this, we should reflect on components of the previously researched physical activity interventions for youth with ASD that may limit the scalability and sustainability of the programs. For example, certain exercise modalities may require specialized settings or equipment (e.g. a pool or equine center), that may incur high costs. Similarly, many exercise interventions examined are dependent on the presence of a specialist, such as a teacher, physical therapist, or occupational therapist. Methods to increase the sustainability and scalability of physical activity interventions must be further researched and refined. The design of interventions should include consideration of eventual expansion to more people and places (scaling-up) and achievement of program maintenance.

1.3. Parent-mediated interventions

In an effort to affect scalable and sustainable change in other domains for the child with ASD, researchers have sought to involve parents in intervention delivery. For example, research has demonstrated the positive effect of parent-mediated interventions for children with ASD, focused on improving adaptive behavior (Tonge et al., 2006), sensory and self-regulatory impairment and autistic behavior (Silva, Schalock, Ayres, Bunse, & Budden, 2009), language development (Siller, Hutman, & Sigman, 2013; Roberts et al., 2011; Jocelyn, Casiro, Beattie, Bow, & Kneisz, 1998), functional emotional development (Pajareya & Nopmaneejumruslers, 2011), joint attention (Kasari, Gulsrud, Wong, Kwon, & Locke, 2010), and social interaction (Casenhiser, Shanker, & Stieben, 2013). Reviews of the literature on parent-mediated interventions for children with ASD have concluded that active parent involvement is an effective and ecological means of intervention delivery (National Research Council, 2001; Oono, Honey, & McConachie, 2013; Pickard, Wainer, Bailey, & Ingersoll, 2016). Yet, parental involvement in physical activity interventions for children with ASD remains limited. In research on the Young Athletes Program (YAP) (Favazza et al., 2013), parents were encouraged to become actively involved in the program and were provided with weekly communications about the YAP activities that could be performed at home with their child. Fidelity of intervention results revealed 46% of the families completed the YAP home record diary, and YAP activities were done on average twice per week. Preliminary analyses showed no significant effects on motor development - the primary outcome - as a result of home-based YAP activities. Hinckson, Dickinson, Water, Sands, and Penman, (2013) also involved parents in their implementation of a weight management program for children with ASD and/or intellectual disabilities. The 10-week program consisted of 18 sessions of physical activity, healthy eating and motivational workshops; parents were encouraged to participate in the physical activity sessions, and, following the physical activity sessions, they attended an hour-long nutrition or motivational segment. Although parents reported positive changes in physical activity, healthy food choices, and overall physical health, significant quantitative improvements were only observed for the six-minute walk-test of physical fitness. Despite a child's level of physical activity being strongly influenced by family factors such as parental expectations and support (Trost et al., 2003), the aforementioned examples of parental involvement in physical activity interventions for children with ASD are the anomalies in research on this topic.

1.4. Project CHASE

To inform future research on parent-mediated physical activity interventions for children with ASD, the current study explores the perspective of parents who participated in Project CHASE (Children with Autism Supported to Exercise). Project CHASE is a webbased, parent mediated intervention that aims to increase physical activity of children with ASD. It involves participating parents joining a private Facebook group, through which they receive daily information (by group posts or private message) targeting one of

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