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Determinants and challenges in physical activity participation in families with children with high functioning autism spectrum disorders from a family systems perspective

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ABSTRACT

The underlying factors affecting physical activity (PA) participation of children with high-functioning autism spectrum disorders (HFASDs) and their family members were investigated using a mixed method research design. Six families with children with HFASD aged 4 through 13 participated in the study. Findings revealed that levels of moderate to vigorous physical activity (MVPA) in children with HFASD varied between 85 min and 405 min for seven days. Parents of children with HFASD in this study were inactive (levels of MVPA varied between 6 min and 53 min) during this period. Qualitative data from parents highlighted many essential issues. Those issues are categorized under three main themes: (a) understanding PA in children with HFASD, (b) living with a child with HFASD, and (c) awareness of autism spectrum disorders (ASD) at school and community settings. Social skills, issues related to bullying, fear of injury to the child, as well as support from family members and lack of understanding of the disability emerged as subthemes extracted from these data.

1. Introduction

1.1. Background information

Recent statistics on children with autism spectrum disorders (ASD) revealed that 1 in 68 children are diagnosed with ASD in United States (Center for Disease Control and Prevention [CDC], 2014). Although each individual displays unique characteristics, children with ASD, including children with high-functioning ASD (HFASD), typically show impairments in social interaction and communication as well as restricted, repetitive and stereotyped patterns of behavior (American Psychiatric Association [APA], 2000). Children diagnosed as having autistic disorder, Asperger's disorder or PDD-not otherwise specified (PDD-NOS), with general cognitive ability and intact language are referred as HFASD in autism literature (Sansosti & Sansosti, 2012; White, Scahill, Klin, Koenig, & Volkmar, 2007). While not used as a diagnostic criterion of ASD, the

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literature reveals that many individuals with ASD display clumsiness, low fitness levels, and developmental delays (Ghaziuddin, Butler, Tsai, & Ghaziuddin, 1994; Manjiviona & Prior, 1995; Rinehart, Bradshaw, Brereton, & Tonge, 2001).

Physical activity (PA) programs have potential benefits for children with ASD if social interactions are positive. These benefits include a decrease in stereotypical and self-stimulatory behavior, improvements in social skills, positive physical functioning, and an increase in on-task behavior in integrated settings including the classroom (Crollick, Mancil, & Stopka, 2006; Lytle & Todd, 2009; O'Connor, French, & Henderson, 2000). In some studies, children with disabilities (including children with ASD) expressed feelings of enjoyment and demonstrated improved recreational skills as a result of participation in swimming classes, gymnastics, or baseball (Castaneda & Sherill, 1999; Fennick & Royle, 2003). The benefits of PA extend throughout the lifespan which can then impact positively on functional daily living skills (Pan & Frey, 2005).

Despite all the benefits of PA on physical and emotional well-being (Edwards, 2006; Lytle & Todd, 2009), children with ASD are mostly engaged in unstructured PA at home such as wandering around the house, being chased by a sibling, jumping, throwing and climbing (Pan & Frey, 2005; Sandt & Frey, 2005). Moreover, many individuals with disabilities including those with ASD are prone to spending large amounts of time watching television and generally leading lives marked by habitual inactivity (Sandt & Frey, 2005). Sandt and Frey (2005), specifically stated that parents use television viewing or video game playing as a tool to occupy their children with ASD, so that they can create time for household duties or interact with other children in the home. Thus, individuals with disabilities are at risk for a lifelong pattern of poor physical and psychological health-related outcomes (Levinson & Reid, 1991; Pan & Frey, 2005).

1.2. Theoretical framework

Researchers attempting to explain family functioning and specifically the role that PA plays in improved cohesion have used systems theory models to advocate for increased PA behavior within a family unit (Ayvazoglu, Oh, & Kozub, 2006; Kozub, 2001). In a more general sense, Turnbull, Turnbull, Wehmeyer, and Shogren (2012) indicate that to promote positive outcomes for children with disabilities, educational and healthcare professionals need to understand relationships between family members. Regardless of the nature of the disability, it is crucial for all children to have functional skills to enhance independence both at home and in the community. Development of physical skills and improvements in health-related fitness have the potential to influence independence in daily life for individuals with disabilities engaged in both home and community activities. This is a major premise of why PA is linked to family function in the lives of individuals with disabilities using systems based principles (Kozub, 2001). Although it is important to understand individual PA behaviors and experiences, it is also important to consider the family as a whole to understand underlying factors affecting the lives of individuals with HFASDs. Several studies suggest that familial context influences the individual's habitual physical activity (Cleland et al., 2011; Fuemmeler, Anderson, & Masse, 2011; Liu, Wiehe, & Aalma, 2014; Loprinzi & Trost, 2010). Families' PA participation is an important determinant of family dynamics (Fuemmeler et al., 2011; Moore et al., 1991). Research suggests that parents play a key role in the development of their child's PA behaviors (Cleland et al., 2011; Fuemmeler et al., 2011; Loprinzi & Trost, 2010). Specifically, parental PA is associated with high levels of children's PA (Fuemmeler et al., 2011). Moore et al. (1991) found that children of active mothers were two times more likely to be active and children who had two active parents were six times more likely to be active than children of parents who were sedentary.

Given the importance of PA and the recent rise in incidence of HFASD, potential relevant factors linked to family PA must be explored. In general, social constraints of youth with HFASD have important PA implications (Pan & Frey, 2005). The current study focused primarily on the issue of PA determinants in children with autism; however, these social constraints are an integral part of PA and inactivity in children with autism (Pan & Frey, 2005; Sandt & Frey, 2005). Further, the notion that children with HFASD are potentially dependent on parents well into adulthood, accents the need for sensitive programming that suits all family members and accommodates youth with HFASD into adulthood (Kozub, 2001). This study builds on previous research and focuses on individuals with HFASD within a family framework in relation to participation in PA at home and in the community. Specifically, the research question guiding this study was the following: what are the determinants and challenges in PA participation in families with children with HFASD from a family systems perspective?

2. Method

2.1. Participants

Six families with a child with HFASD were recruited from family conferences, regional parent support group meetings, and through direct contact, using a criterion-sampling approach based on having a child with ASD and having all family members residing in the same home with at least one parent or caregiver. Children with HFASD had to meet the following criteria in order to participate in the study: (a) qualify for or be currently receiving special education services under the diagnosis of ASD (APA, 2000), (b) have verbal communication and average cognitive functioning (Sansosti & Sansosti, 2012; White et al., 2007), (c) have not been diagnosed as having any other co-existing conditions that interfered with PA. Because the children's personal information was not accessible to the researcher, children with HFASD diagnosed as having HFA, autism, Asperger's syndrome or pervasive developmental disorder – not otherwise specified (PDD-NOS) reported by parents based on school and/or medical diagnosis procedures, were recruited. The average age of children with ASD was $M = 7.5$ years. Signed informed consents were secured from all participants and study activities followed documented