Health-related quality of life in children with Developmental Coordination Disorder: Association between the PedsQL and KIDSCREEN instruments and comparison with their normative samples

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ABSTRACT

Background and aims: One of the major concerns for Developmental Coordination Disorder (DCD) are the mental and physical consequences of the condition, especially as they relate to quality of life factors. Here, we examined health-related quality of life (HRQOL) in children with DCD, determined the association between two standardized parent reports, and compared HRQOL of our sample with DCD with the normative sample of each assessment for typically developing (TD) children and a sample of children with chronic health conditions.

Methods and procedures: Parents of children with reported DCD with ages between 6 and 12 completed the PedsQL and KIDSCREEN instruments through an online survey. The PedsQL measures HRQOL in the Physical, Emotional, Social, Academic, and Psychosocial Functioning domains, while the KIDSCREEN assesses HRQOL in Physical and Psychological Well-Being, Autonomy & Parents, Peers & Social Support, and School Environment.

Outcomes and results: Pearson’s correlation analyses showed low to moderate correlations between dimensions of the assessments, with the exception of the KIDSCREEN Autonomy & Parents. T-test analyses showed that the group with DCD showed significantly lower scores than the normative samples on the PedsQL and KIDSCREEN, and the PedsQL scores were significantly lower than those of a sample of children experiencing chronic illness.

Conclusions and implications: Scores on both instruments state that DCD likely represents a serious problem for children, and add to the body of evidence supporting the notion that children with DCD have lower overall HRQOL. We urge professionals to address or refer these children to services that can help improve children’s quality of life and prevent future health problems.

What this paper adds:

Developmental Coordination Disorder (DCD) is one of the major health problems among school-aged children worldwide. This paper investigated health-related quality of life (HRQOL) in children with DCD using two assessments, the PedsQL and KIDSCREEN. The paper adds to the extensive body of literature supporting the notion that children with DCD have significant problems on overall HRQOL. Furthermore, the present study highlights how parents of children with DCD reported significantly lower scores in both assessments, when compared to the normative samples of each instrument and a sample of children experiencing chronic illness. The

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results establish the fact that children with DCD are susceptible to severe consequences for HRQOL, and calls practitioners and researchers to action.

1. Introduction

Developmental Coordination Disorder (DCD) is a motor skill disorder characterized by a marked impairment in the development of motor coordination that interferes with academic and social functioning, and occurs despite environmental opportunities for optimal development (APA, 2013). In general, children with DCD struggle with performing motor skills and everyday activities, such as tying shoes, buttoning a shirt, or using cutlery. Those general difficulties can be observed at different levels – when children with DCD attempt to plan a motor task, organize movements, perform a coordinated action, and adjust movements when demands change, such as moving fast to catch a ball (Caçola, 2014). Currently, it is estimated that 5–6% of school-aged children have DCD (APA, 2013), which makes the disorder one of the major health problems among school-aged children worldwide (Missiuna, Moll, King, Stewart, & Macdonald, 2008). Most importantly, the outcomes of DCD often extend beyond the motor domain to include secondary mental and physical health issues (Green, Baird, & Sugden, 2006; Missiuna, Gaines, Soucie, & McLean, 2006; Missiuna, Moll, King, & Law, 2007).

One of the major concerns for children with DCD are these mental and physical consequences of the condition (Caçola, 2016), especially as they relate to quality of life (QOL) factors. Here, we explored health-related quality of life (HRQOL) in this population. HRQOL is a multidimensional construct referring to the impact of a condition on physical, emotional, social, and school well-being (Brown et al., 2016). While the research exploring these factors in individuals with DCD is extensive for many aspects (Zwicker, 2016), few studies have explored the broader concept of HRQOL for these children and their families. For example, Wang and Huang (2012) tested HRQOL in parents and children diagnosed with DCD. Results of the study indicate that children with DCD had significantly lower HRQOL in all psychosocial domains when compared to typically developing (TD) children, and the degree of reduction was associated to level of motor proficiency. Interestingly, the authors also found that parents of children with DCD had significantly lower QOL than parents of TD children. The authors used the Child Health Questionnaire-Parent Form 50 assessment for children and the Short Form Health Survey (SF-12), Beck Depression Inventory (BDI), and Beck Anxiety Inventory (BAI) instruments for parents. However, the parental perception of the child’s HRQOL was not assessed.

Another aspect that can affect quality of life in the DCD population is the type and number of conditions diagnosed in a child. Flapper and Schoemaker (2008) established that a sample of children with DCD combined with attention deficit hyperactivity disorder (ADHD) reflected a lower general well-being than healthy TD children, but also found that QOL improved after children started taking medication for ADHD. Flapper and Schoemaker (2013) found that children with Specific Language Impairment (SLI) and DCD had significantly lower QOL scores than children with SLI only. These findings lead us to believe that co-morbidities can have a significant impact on quality of life, and should be accounted for in investigations of HRQOL. Both studies used the TNO-AZL-Child-Quality-Of-Life (TACQOL) questionnaire to determine HRQOL.

Recently, Raz-Silbiger and colleagues (2015) evaluated leisure time and temporal aspects of HRQOL by investigating children’s motor deficits and levels of activeness in relation to seasonal participation (specific times – school year versus summer and weekends). Results were somewhat surprising in the sense that there was only a low, but significant correlation between motor skills and children’s HRQOL. The authors explained that social interactions also happen through screen related activities, which could have contributed positively to HRQOL in this population. In addition, the authors found a seasonal effect on HRQOL, which could be related to an influence of participation and issues in school compared to summer vacation and weekends, especially in the population with DCD. However, the authors caution of the small sample size and generalization of the results. The Pediatric Quality of Life Inventory (PedsQL 4.0 Generic Core Scales; Varni, 2005) was used in this study, but as previously mentioned, the sample size was small (n = 22 in the DCD group). Therefore, further investigations of HRQOL in children diagnosed with DCD and their families, and the use of distinct assessments to measure that construct, remain lacking in the research literature.

For that reason, the general purpose of the present study was to examine HRQOL in children with DCD using two standardized parent reports for evaluation of HRQOL. In addition, we aimed to determine the association between these two well-known instruments to determine whether the results are consistent across assessments. To that goal, we used the PedsQL (Varni, 2005), which has been previously used by Raz-Silbiger et al. (2015), and the KIDSCREEN (Ravens-Sieberer & K_idscreen Group Europe, 2006), never previously used with children with DCD. Both instruments were designed to measure HRQOL in children, but each measure focuses on different aspects of HRQOL in social support, functioning with peers, and relationships with parents compared to the child’s reported autonomy. A secondary purpose of this study was to compare HRQOL of our sample reported to have DCD with the normative sample of each assessment (TD children), and a sample of children reported to be living with a chronic health condition (PedsQL). We chose to specifically compare our sample with a sample with chronic health conditions – defined as physical or mental health conditions impairing children’s activities (Varni, Burwinkle, & Seid, 2006) in order to determine the contrast of HRQOL in these two types of chronic problems, as DCD is also considered a chronic condition. This study is unique because it assesses HRQOL with two instruments, one being novel in the DCD literature (KIDSCREEN). We expected to find a significant association of HRQOL scores from both instruments. We also predicted that the population with DCD would show lower scores than the normative samples of TD children for both assessments, but higher scores than the population with chronic health conditions of the PedsQL. We expected these higher scores because pediatric populations with chronic health conditions have documented psychological and social at-risk status (Wallander & Varni, 1998).
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