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Health-Related Quality of Life in Children with Developmental Disorders

Marina M. Schoemaker¹ · Suzanne Houwen²

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Abstract

Purpose of Review (1) To give an overview of what is currently known about health-related quality of life (HRQoL) in three common and co-occurring developmental disorders: attention deficit hyperactivity disorder (ADHD), autism spectrum disorders (ASD), and developmental coordination disorder (DCD), and (2) to provide directions for future research.

Recent Findings HRQoL is compromised in all three developmental disorders, affecting various domains of HRQoL. However, some domains are more affected than others depending on the nature of the core deficits of the disorder. Overall, parents' rate HRQoL of their children lower than the children themselves. Children with ASD and ADHD with co-occurring disorders have lower HRQoL compared to those with singular disorders. Future studies in DCD are needed to investigate the effect of co-occurring disorder in this population.

Summary Children with developmental disorders have lower HRQoL than typically developing children. Future research should focus on the effects of co-occurring disorders on HRQoL and on protective factors that may increase HRQoL. HRQoL should be a part of clinical assessment, as it reveals the areas in life children are struggling with that could be targeted during intervention.

Keywords Quality of Life · ADHD · ASD · DCD · Resilience

Introduction

Assessment of health-related quality of life (HRQoL) in children with a developmental disorder may provide insight into the impact of a disorder across several life domains, which accordingly could be targeted through intervention [1•]. The ultimate goal of intervention in children with developmental disorders is to lessen the impact of the disorder on well-being and daily functioning. Consequently, assessment of HRQoL has become essential to develop interventions to improve treatment outcome in both clinical research and health care [1•, 2]. An intervention can only be regarded effective if it

improves the core symptoms of a disorder but also diminishes its impact on daily life [1•]. In the following, an overview will be given about the state of the art of research concerning HRQoL in three common and often co-occurring developmental disorders: attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), and developmental coordination disorder (DCD). We will highlight which domains HRQoL is lower for each disorder, which factors are related to lower HRQoL (such as severity of the disorder and the presence of co-occurring disorders), and which factors may protect children from lower HRQoL (such as support from parents or self-esteem). In addition, we will discuss the reliability and validity of child versus proxy-reported HRQoL. Finally, directions for future research will be discussed and implications for health-care will be provided.

This article is part of the Topical Collection on *Comorbidities*

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Health-Related Quality of Life

The World Health Organization (WHO)'s International Classification of Functioning, Disability, and Health (ICF) is one of the most commonly applied frameworks to the concept of quality of life (QoL) [3]. According to the WHO, QoL is "the individual's perception of their position in life, in the

context of culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns” [4]. HRQoL is the perceived impact of a health condition and its treatment on well-being and functioning in daily life of an individual [5]. However, the concepts QoL and HRQoL are defined inconsistently and often used interchangeably [6, 7]. To put it broadly, QoL is the broader term encompassing how a person evaluates multiple aspects of his/her life, with HRQoL only encompassing the subjective evaluation of those aspects of QoL affected by a health condition [8]. HRQoL is an equivocal concept with many definitions and means of measurement [5]. The common ground of most definitions is that it is a multidimensional, dynamic construct, which covers at least three domains, i.e., physical, psychological, and social functioning. Physical functioning includes pain and discomfort, energy, and fatigue; psychological functioning includes cognitive and affective well-being; and social functioning includes peer and family relationships [4]. It is noteworthy that there is significant heterogeneity in how these domains are labeled and subdivided [8]. The focus of the present paper is on the impact of developmental disorders on HRQoL.

More than 90 instruments have been developed to measure HRQoL in children [9]; yet, no gold standard is available [10]. This hampers comparisons across studies as these instruments often measure different subdomains of HRQoL [11]. HRQoL instruments can be divided into generic instruments and disease-specific instruments. Generic instruments are usually less able to capture the disease-specific impact on HRQoL [9]. Their advantage, however, is that they enable comparison of HRQoL across a range of disorders and between children with a disorder and typically developing (TD) children [12]. Disease-specific instruments are generally more sensitive to the effects of an intervention, as they better capture the specific impact of a disorder [12]. Another distinction related to the assessment of HRQoL is child self-report versus proxy report (parents or caregivers reporting on the child’s behalf). The common viewpoint is that child self-report is preferred as children themselves can best reflect on the perceived impact of a disorder on their life [13]. However, proxy report is required with very young children or children who lack the attention, language, or cognitive abilities to fill out a questionnaire. Their interpretation of the questions may differ or they take a different time perspective into account when answering questions [14]. In the next paragraphs, a summary is given of what is currently known about HRQoL outcomes in three prevalent developmental disorders, ASD, ADHD, and DCD that often co-occur. Although the impact of these disorders on HRQoL continues into adolescence and adulthood [15–17], the focus of this paper is primarily on HRQoL in childhood. Knowledge on HRQoL in childhood is paramount to inform the development of intervention programs that target the negative impact of a disorder, which accordingly prevents the cascading influence of low perceived HRQoL later in life.

HRQoL in Children With ASD

The core characteristics of ASD are impairments in social interaction and communication, in addition to restricted, repetitive patterns of behavior, interests, and activities [5]. Prevalence rates for ASD vary worldwide from 0.8 to 93 per 1000 people, with higher prevalence rates in Australia and Asia compared to Europe [18]. ASD is seldom the only disorder present; co-occurring disorders have been found in about 85% of children with ASD, such as behavioral disorders (in particular ADHD), intellectual disabilities, and psychiatric disorders (i.e., anxiety, depression, obsessive-compulsive disorder, and oppositional defiant disorder) [19]. Also, DCD frequently co-occurs with ASD [20]. According to a recent study, 86.9% of children with ASD are at risk for DCD on the basis of parents’ reports on the Developmental Disorder Coordination Questionnaire (DCDQ) [21].

HRQoL of children with ASD is poorer than that of TD children with significantly lower scores on all domains measured in children with ASD [5, 22•, 23–25]. Not unexpectedly, the social domain has been reported to be the most affected [18, 24, 25]. Interestingly, the research findings also clearly highlight that the consequences for HRQoL are more widespread than the social domain only and are not uniform for children with ASD. A recent study identified five different HRQoL profiles in children and adolescents with ASD, with one profile having a low risk for HRQoL impairments (19%), a profile with school problems (21%), a profile with social-emotional problems (25%), and two profiles with both physical and social-emotional problems with the level of physical problems (including both medical and motor problems) differing between these two groups (46%) [26•]. Interestingly, children in the low risk group were significantly younger than the children in the other profiles. This may suggest that older children become more aware of their activity limitations, which is reflected in lower HRQoL [26•]. Although scores on HRQoL domains are lower in children with ASD compared to TD children irrespective of whether child self- or parent proxy-reports were used, the child self-report scores of children with ASD are generally higher than those of their parents’ proxy reports [5]. Furthermore, it is important to note that studies that used self-reports to investigate HRQoL in children with ASD typically included only children who were high functioning, as children with cognitive and language disabilities or children who were nonverbal may not have been able to understand or answer the questions.

Several factors have been associated with HRQoL in ASD. The presence of fewer behavioral problems [24, 27] and also less social impairment, fewer repetitive behaviors, and fewer signs of internalizing and externalizing problems are related to higher HRQoL [24, 28•]. Likewise, higher self-esteem and fewer symptoms of internalizing problems such as anxiety and depression are associated with higher HRQoL [5].

Remarkably, HRQoL in ASD is lower among children with less severe ASD symptoms who attend regular education. This could be because TD peers do not recognize these children's behaviors as symptoms associated with a disorder, but rather as weird behaviors, which can result in teasing, bullying, and exclusion [29]. According to a recent review and meta-analysis, about 50% of the children with ASD are bullied, particularly those in regular education settings [30].

HRQoL in Children With ADHD

The main characteristics of children with ADHD are inattentiveness, hyperactivity, and impulsive behavior [31]. ADHD has an estimated prevalence of 7.2% worldwide [32]. Co-occurring problems are common. According to a study in the USA, in 2015, the most prevalent co-occurring disorders are behavioral and conduct disorders (51.5%), anxiety (32.7%), depression (16.8%), and ASD (13.7%) [33]. In this study, the co-occurrence with DCD was not taken into account, but according to the results of another systematic review, DCD occurs in about 50% of children with ADHD [34].

The disorder is associated with lower HRQoL, with lower scores in the psychological and social domain (emotions and interpersonal relationships), the school domain (academic performance), and the family domain (family life) [10, 25, 35, 36]. The scores for the physical domain are generally not or only slightly lower in ADHD [10, 36] compared to TD children. These findings hold for both parent proxy report and child self-report, although children give a more positive picture of their HRQoL than their parents [1, 10]. The agreement between parents and children is better for the physical domain than for the psychological and social domains, probably because the impact on the physical domain can be more reliably observed by parents [1, 37]. Similar to the findings in children with ASD, the older the children, the lower HRQoL [36]. An important finding with a view to intervention is that, when core ADHD symptoms improved over time, they were only marginally associated with a change in HRQoL over time [38]. This is in line with a study investigating the effects of medication on ADHD symptoms and HRQoL in children with ADHD [11]. Although both ADHD symptoms and HRQoL improved after medication, HRQoL was still lower than that of TD peers [11]. This implies that other factors beyond core ADHD symptoms influence HRQoL in children with ADHD.

Factors that have been found to negatively influence HRQoL are the severity of the disorder [1, 10], the presence of co-occurring disorders [10], peer problems [39], sleep problems [38], and having a parent with (mental) health problems due to the child's ADHD [39]. However, in the absence of co-occurring disorders, HRQoL is still affected in children with ADHD [35]. Research regarding factors that positively influence HRQoL is scarce. One factor that has been found to have a positive impact on HRQoL is an authoritative parenting style [40].

HRQoL in Children With DCD

Children with DCD have difficulties with the coordination of fine and gross motor skills, which affects their performance in activities of daily living (ADL) and sports and leisure activities. The coordination difficulties cannot be explained by intellectual disability or a neurological condition [31]. Generally, prevalence figures of 5 to 6% are reported in the literature [41]. DCD is also not a "pure" disorder, indicating again that co-occurring conditions such as ADHD [42, 43], specific language impairment [44], and ASD [45] are the rule rather than the exception.

Compared to ASD and ADHD, HRQoL has been a neglected field in DCD research [46]. The few studies that have been done reveal lower HRQoL in children with DCD compared to TD children, with the physical domain and also the psychological and social domains affected [47, 48, 49]. These findings are irrespective of whether HRQoL is measured by child- or parent-proxy report and highlight that the impact of DCD stretches beyond the motor domain. Although both child- and parent-proxy reports on HRQoL are lower in children with DCD compared to TD children, parents report lower HRQoL in more domains than their children [47, 48]. The impact of DCD on HRQoL is seen in more than just the motor domain which is supported by the results of a qualitative study in which children with DCD were interviewed about the impact of DCD on their lives [46]. Children reported that they struggled with ADL and self-care activities, and also with frustration and sadness due to their repeated failure in these activities. Their inability to successfully participate in sports and games often leads to exclusion, teasing, or even bullying [46].

DCD is a so-called hidden disorder meaning that peers do not recognize the motor problems as signs of a disorder. Consequently, TD children, but also teachers and parents, are generally not aware that the coordination difficulties are caused by an underlying disorder and attribute the motor problems to laziness or lack of effort. Negative reactions from peers may lead to withdrawal from sports and games, which in turn negatively influences their motor performance and social acceptance. Less acceptance and criticisms by peers may lead to lower HRQoL.

Studies investigating factors associated with lower HRQoL in children with DCD are scarce, but severity of DCD is associated with lower HRQoL [49]. In addition, one study addressed the relation between participation in physical activities and HRQoL [50]. Children with DCD who participated more in vigorous physical activities showed higher parent-rated HRQoL in the social domain than children who participated less in vigorous activities [50]. More research is needed to investigate which factors have either a positive or negative impact on HRQoL in children with DCD [51].

Child Versus Proxy Report

The majority of studies measuring HRQoL in children with ADHD and ASD have used parent proxy-reports only [1•, 22•, 36•] while the few studies measuring HRQoL in DCD included both parent proxy-reports and child self-reports of HRQoL [47•, 48, 49]. When both parent and child perspectives of HRQoL are taken into account, the correlations between parent and child reported HRQoL are generally positive, but low-to-moderate [10, 52]. This not only implies an association between parents' and children's perspectives of the child's HRQoL [11] but also that the perspective of parents cannot be used in place of the child's perspective, as parents generally rate their child's HRQoL as lower than their child on most domains. The reason that the parent proxy reports of HRQoL predominate in the literature is that young children are assumed to be less able to reflect on their HRQoL [3]. Interestingly, when age-appropriate measurement instruments were used, TD children as young as 5 were able to reliably reflect on their own HRQoL [53, 54]. The consistently more favorable outcome on HRQoL measures of children compared to parents reflects that children have a different view on their HRQoL. It is important to clarify why views on HRQoL differ between parents and children [14]. In the case of ADHD, it is possible that their impulsiveness may induce answering the questions by reflecting on how they feel at that particular moment, instead of how they feel in general [10]. Moreover, a positive illusory bias may be prevalent among children with ADHD that results in children with ADHD answering questions related to their HRQoL in a more positively biased manner in order to protect a positive self-image [10]. Indeed, self-reports of children with ADHD related to their abilities (e.g., academic performance, social acceptance) were found to be more positive than their actual performance [55]. For children with ASD, their ability to reliably reflect on their HRQoL has been questioned [5, 22•]. This is especially true for low-functioning children with ASD, as their cognitive and language disabilities may prevent them from understanding and interpreting the questions that are typically asked on measures of HRQoL [5, 22•]. However, most research regarding child self-reported HRQoL has involved children with high-functioning ASD [5]. The reliability and validity of child-reported HRQoL are that children with DCD still need to be investigated

An important question in need of future research is why parents tend to rate the HRQoL of their children with a developmental disorder lower than the children themselves. Possibly, the stress they experience in caring for a child with a developmental disorder induces perceptions of poorer HRQoL in their child [29, 37, 53]. The validity of this explanation was recently supported in a study of children with ADHD, which found that higher parental stress levels were

associated with lower parent HRQoL ratings of their child [1]. If parents feel less in control and experience more stress when raising a child with ADHD, this could be reflected in how they perceive the impact of the disorder on their child's HRQoL. Whether this is a common finding in ADHD and whether this is also true for other developmental disorders remains to be further investigated. In addition, parents may also value quality of life domains differently than their children. For instance, parents of a child with ASD may consider social interaction with peers important, whereas the child is less interested in social interaction [5]. Research should not only take into account how HRQoL is rated but also the importance of skilled functioning in a particular domain for the child and parent.

Despite the abovementioned caveats, both child and proxy reports are recommended to provide a comprehensive impression of HRQoL in children with developmental disorders. Both may provide valuable information about HRQoL, as it reflects the perspective of both child and parent. It is unknown which viewpoint is more reflective of HRQoL, as both may be subject to response bias. In case of substantial differences between child and parent ratings of HRQoL, a health professional may explore the source of these differences. Parents may be unnecessarily concerned about their child's well-being, or relational problems between parent and child may be at stake, leading to a poor perspective of a child's well-being [1].

Future Directions for Research: Protective Factors

In general, the focus of research concerning HRQoL in children with developmental disorders has predominantly been on risk factors that are associated with increased vulnerability for poorer HRQoL. However, poor HRQoL is not found in all children with developmental disorders. Some seem more resilient than others to the personal, social, and environmental stressors that are associated with poorer HRQoL. Resilience is the ability to cope with stressors that may negatively affect well-being [56–58]. Both personal and social/environmental protective factors can promote resilience; better resilience may lead to improved coping with the consequences of a health condition, which may result in better HRQoL [59]. In TD children, several protective factors have been identified that are related to good HRQoL, including self-esteem, optimism, a positive family climate, and social support [60•]. Less is known about protective factors in children with developmental disorders. Yet, identification of protective factors is important for the development of intervention programs. The aim of an intervention should not only be to alleviate the core symptoms of a

disorder but also to improve HRQoL. Strengthening of protective factors may be an important means to reach this goal.

What is currently known about protective factors related to better HRQoL in children with developmental disorder? In children with ADHD, research has directly examined protective factors for HRQoL. In a review by Dvorsky and Langberg, several protective factors were identified as promoting HRQoL [61••]. In particular, positive self-perception, positive parenting, and social acceptance were found to provide buffers against the negative effects of ADHD-related symptoms [61••]. To date, studies concerning protective factors in individuals with ASD are scarce [62] and mainly focused on protective factors for the development of internalizing symptoms [63], assuming that less internalizing symptoms would lead to better HRQoL. More specifically, the studies particularly focused on positive parenting and positive peer relationships as protective factors. The results of the review showed that, in regard to positive parenting studies, results were inconclusive, but positive peer relationships were found to act as a protective factor for internalizing problems [63]. In DCD, the focus of research has mainly been on protective factors that increase resilience to mental health problems, such as high IQ, high self-esteem, good social communication skills, and absence of bullying [64]. As the presence of mental health problems is related to lower HRQoL [10], it is likely that factors that promote resilience to mental health problems are also associated with higher HRQoL in children with DCD.

Empowerment of children with development disorders may also act as a protective factor for HRQoL. Outlining their strengths, needs, and difficulties, and how to deal with their difficulties in a constructive way may give children tools to cope with the impact of a disorder [29]. For instance, two coping strategies were identified in interviews with children with DCD about the impact of the disorder, namely, emphasizing their strengths and thinking differently [46•]. By focusing on their strengths (e.g., activities they are good at) instead of their weaker points (e.g., their motor problems), children managed to preserve a more positive self-image. Also, telling themselves that their disorder does not define them (e.g., thinking differently) helped the children with DCD to cope with their developmental problem [46•]. Thus, a strength-based approach may help to empower children in their struggle with the day-to-day consequences of their disorder(s). Strategies to enhance empowerment of children may further help to boost HRQoL. Future research should focus more on protective factors that are associated with better HRQoL in children with developmental disorders. Accordingly, knowledge about these protective factors could be implemented in intervention programs to lessen the burden of these developmental disorders and promote better HRQoL.

Conclusions

The impact of a developmental disorder stretches beyond the core deficit domains of the disorder and can become visible in other domains of development such as mental health and HRQoL. People working with children with developmental disorders need to be alert to low levels of HRQoL in different domains of functioning, and their need of support and intervention in these domains [18]. Research has reported that HRQoL is significantly lower in children with developmental disorders, irrespective of whether the disorder of concern is ADHD, ASD, or DCD only or whether these disorders co-occur. However, children with ASD and ADHD with co-occurring disorders experience lower HRQoL than those without co-occurring disorders. Whether the same holds for children with DCD still needs to be investigated. Remarkably, hardly any studies addressed how HRQoL develops over time in children with developmental disorders with and without co-occurring disorders. Longitudinal studies are required to address this topic.

Although HRQoL is an important outcome measure of treatment, it is seldom assessed in intervention studies as a treatment outcome because the focus is on improvement of the core deficits of a disorder. Therefore, measurement of HRQoL is recommended as part of the assessment of treatment outcomes in children with developmental disorders. Improvement of HRQoL should be included as one of the treatment outcomes assessed in addition to the core aspects of a developmental disorder. If the core aspects improve, but HRQoL is still low in some domains, this may indicate that additional support is needed in those domains. Knowledge about protective factors that are associated with HRQoL is essential to enhance the effectiveness of intervention strategies for children with ASD, ADHD, and DCD.

Declarations

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

Conflict of Interest The authors declare no competing interests.

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