



The relationship between Health-Related Quality of Life and sleep problems in children with Autism Spectrum Disorders



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ABSTRACT

Although children with Autism Spectrum Disorders (ASD) are thought to experience sleep problems at a much higher rate than typically developing peers, the relationship between sleep disturbance and Health-Related Quality of Life (HRQoL) has not been explored within this pediatric population. Further, little is understood about the HRQoL of children with ASD in general. This study assessed the HRQoL and sleep health of a sample of children with ASD and investigated the relationship between HRQoL and overall sleep problems within the context of key clinical characteristics. Study participants included 86 parents of children with ASD between the ages of 4 and 12 years. Subjects were recruited from 3 autism specialty clinics at large academic medical centers and asked to proxy-report on their children's HRQoL and sleep habits. Adjusted regression models showed a consistent negative relationship between sleep disturbance and HRQoL, with greater overall sleep problems being associated with poorer total, physical, and psychosocial HRQoL. Sleep duration and sleep anxiety were also found to be negatively associated with HRQoL. These findings suggest that treatments that are effective in treating sleep disturbances may improve children's HRQoL.

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1. Introduction

Health-Related Quality of Life (HRQoL) is a comprehensive approach to health outcome measurement that is intended to assess an individual's overall level of functioning and well-being. In comparison to other methods of health measurement, HRQoL assessment is distinguished by its multi-dimensional nature and its focus on capturing subjective experiences of health, emphasizing an individual's perception of his/her well-being rather than objective indicators of health. At a minimum, standardized HRQoL assessments measure the physical, cognitive, psychological and social aspects of health and functioning. However, many instruments evaluate additional, more specific areas of well-being, such as family cohesion and

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self-esteem. While HRQoL instruments may be used to assess generally healthy populations, they are often used to evaluate the impact of an illness and its treatment on individuals with chronic conditions.

All standardized HRQoL instruments come in the form of a generic or condition-specific questionnaire. The latter type of survey is designed to evaluate health and functioning amongst individuals who have a particular condition or illness, while generic HRQoL assessments are intended to measure well-being across different health states. Generic assessments therefore allow for direct comparisons between healthy normative populations and populations with chronic conditions. In recent years, HRQoL has gained increasing attention as an important outcome to measure in the assessment of pediatric interventions and clinical trials and is frequently used to evaluate outcomes among children with chronic medical conditions. Due to its comprehensive and multidimensional nature, HRQoL measurement is particularly well-suited to evaluate conditions that have a multi-dimensional impact, such as Autism Spectrum Disorders (ASD).

ASDs are a group of pervasive developmental disorders characterized by deficits in communication and social reciprocity and the presence of restricted interests and repetitive behaviors (American Psychiatric Association, 2000). This group of disorders is further distinguished by marked heterogeneity and high rates of psychiatric and physical co-morbidities. In addition to having significant difficulty interacting socially and recognizing and understanding emotions, children with ASD have been shown to experience more stress, depression, and anxiety than typically developing peers (Corbett, Schupp, Levine, & Mendoza, 2009; Hobson, Lee, & Hobson, 2009; Hobson, Hobson, Malik, Bargiota, & Calo, 2013; Kanne, Abbacchi, & Constantino, 2009; MacNeil, Lopes, & Minnes, 2009; Mayes, Calhoun, Murray, Ahuja, & Smith, 2011; Mayes, Calhoun, Murray, & Zahid, 2011; Rump, Giovannelli, Minshew, & Strauss, 2009; Spratt et al., 2012; Uljarevic & Hamilton, 2013; Watson, Crais, Baranek, Dykstra, & Wilson, 2013; Weigelt, Koldewyn, & Kanwisher, 2012; White, Oswald, Ollendick, & Scahill, 2009). This pediatric population has also been found to have a higher prevalence of sleep problems, gastrointestinal disorders, and respiratory, skin, and food allergies (Adams, Johansen, Powell, Quig, & Rubin, 2011; Angelidou et al., 2011; Badalyan & Schwartz, 2012; Cortesi, Giannotti, Ivanenko, & Johnson, 2010; Gurney, McPheeters, & Davis, 2006; Ibrahim, Voigt, Katusic, Weaver, & Barabresi, 2009; Jyonouchi, 2010; Richdale & Schreck, 2009; Shibata et al., 2013; Tudor, Hoffman, & Sweeney, 2012; Wang, Tancredi, & Thomas, 2011). Despite the high prevalence of psychosocial and physical co-morbidities, little is understood about the overall HRQoL of children with ASD. The few studies that have been published on this topic, however, report children with ASD to have significantly lower HRQoL scores than their typically developing peers when assessed with generic assessment tools (Kamp-Becker et al., 2011; Kuhlthau et al., 2010; Lee, Harrington, Louie, & Newschaffer, 2008; Limbers, Heffer, & Varni, 2009; Shipman, Sheldrick, & Perrin, 2011). While these studies found children with ASD to have poorer overall HRQoL, they also showed evidence of lower social, emotional, physical and school functioning. This research has additionally shown an inverse relationship between HRQoL and behavior problems, with poorer quality of life being associated with more severe internalizing and externalizing behaviors, increased repetitive behavior, and poorer adaptive and social behaviors (Kamp-Becker, Schroder, Remschmidt, & Bachmann, 2010; Kuhlthau et al., 2010, 2013; Limbers et al., 2009; Steensel, Bogels, & Dirksen, 2012). A negative association between anxiety and HRQoL was also reported in two recent studies (Shipman et al., 2011; van Steensel et al., 2012).

Sleep problems are among the most prevalent of co-morbidities experienced by children with ASD, with 40–80% of this pediatric population estimated to experience some type of sleep disturbance (Cortesi et al., 2010; Hollway & Aman, 2011; Johnson & Malow, 2008b; Malow, 2004; Richdale & Prior, 1995; Richdale & Schreck, 2009; Wiggs & Stores, 2004; Williams, Sears, & Allard, 2004). This compares to a prevalence rate of 25–40% for typically developing children (Hollway & Aman, 2011). Evidence indicates that children with ASD experience a wide range of sleep issues, with many children experiencing multiple problems concurrently. While some of the most commonly reported problems are symptoms of insomnia, such as problems with sleep maintenance, sleep duration and delayed sleep onset (Cortesi et al., 2010; Johnson & Malow, 2008a, 2008b; Liu, Hubbard, Fabes, & Adam, 2006; Malow, 2004; Richdale & Schreck, 2009; Wiggs & Stores, 2004), other frequently reported issues include problems with daytime sleepiness, sleep apnea, parasomnias, settling difficulties, early morning waking, and restless leg syndrome (Cortesi et al., 2010; Liu et al., 2006; Malow, 2004; Richdale & Schreck, 2009; Wiggs & Stores, 2004; Williams et al., 2004). Accordingly, there does not appear to be one particular sleep problem that characterizes children with ASD, but many. The experience of such sleep problems has been found to be significantly associated with autism symptom severity, including greater difficulty with communication, social skills, and restricted and repetitive behaviors (RRBs) (Cortesi et al., 2010; Goldman et al., 2009; Hollway & Aman, 2011; Malow, McGrew, Harvey, Henderson, & Stone, 2006; Richdale & Schreck, 2009; Schreck, Mulick, & Smith, 2004), as well as with increased internalizing and externalizing behavior and poorer adaptive skill development (Sikora, Johnson, Clemons, & Katz, 2012). Sleep problems have also been associated with certain medical and mental health conditions among children with ASD, such as ADHD, asthma, allergies, gastrointestinal problems, anxiety, and depression (Cortesi et al., 2010; Hollway & Aman, 2011; Liu et al., 2006; Richdale & Schreck, 2009).

Despite the prevalence of sleep problems among children with ASD and evidence of the adverse effects of such problems, to our knowledge, the relationship between sleep disturbances and HRQoL has not yet been explored among this group. However, this relationship has been studied in other pediatric populations, with research indicating that individuals with sleep problems experience poorer HRQoL than those without sleep issues (Crabtree, Varni, & Gozal, 2004; Hart, Palermo, & Rosen, 2005; Hiscock, Canterford, Ukoumunne, & Wake, 2007; Rosen, Palermo, Larkin, & Redline, 2002). In a study of a community sample of 4983 pre-school-aged children, individuals with sleep problems were found to have poorer overall HRQoL than children without problems, as well as lower physical, cognitive, social and emotional functioning (Hiscock et al., 2007). Similarly, research on 80 children referred to a sleep disorders clinic found those with sleep disturbances to have

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