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Health-related quality of life and its determinants among adults with autism



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ABSTRACT

The purpose of this study was to determine health-related quality of life (HRQOL) among adults with autism, and compare it to the HRQOL of the general adult population in the United States (US). Factors predicting HRQOL of adults with autism were also identified. A cross-sectional online survey was conducted to gather study information. From adults with autism registered with the Interactive Autism Network (IAN), those aged 18 years and above and having the capacity to self-report were identified and approached for study participation. The final sample included 291 adults with autism. One-way *t*-test revealed adults with autism to have significantly lower physical and mental HRQOL than their counterparts in the US population. Using linear regression analysis, modifiable factors including social support and coping along with other socio-demographic and medial characteristics were identified as significant predictors of physical and mental HRQOL. Greater perceived adequacy of social support from friends and family was associated with better HRQOL, while greater use of maladaptive coping was associated with lower HRQOL. Clinicians and other health interventionist should consider assessing these factors among adults with autism, and provide necessary capabilities to these adults with the aim of improving their HRQOL.

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1. Introduction

Autism encompasses a group of neurological developmental disorders that are associated with limitations in social and communication skills and restricted and repetitive behaviors (American Psychiatric Association, 2000). Autism is a spectrum disorder that includes autistic disorder, Asperger's syndrome, and pervasive developmental disorder-not otherwise specified (PDD-NOS). One in 88 children have autism in the United States (US) (Baio, 2012). The prevalence of autism is ~5 times higher among boys as compared to girls (Baio, 2012). Given the psychosocial limitations imposed by autism, there is a significant financial burden associated with this disorder (Ganz, 2006, 2007; Liptak, Stuart, & Auinger, 2006; Lokhandwala, Khanna, & West-Strum, 2012). The total (direct and indirect) lifetime per capita societal cost of autism is \$3.2 million, with

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lost productivity and adult care being the main cost drivers (Ganz, 2007). Based on recent estimates, the direct and indirect costs of autism are said to be \$137 billion each year in the US (Autism Speaks, 2013).

A great deal of literature in autism has focused toward studying outcomes among children with the disorder, with limited research being done in adults. Epidemiological data on autism prevalence among adults in the US is currently lacking; however, studies conducted abroad have found prevalence rates among adults to mirror those among children (Brugha et al., 2011). Considering that the physical and environmental factors that interplay with autism symptoms are markedly different between children and adults, research done among children with autism cannot be extrapolated to adults with the disorder. Autism is a chronic disorder, and its impact varies across the lifespan of an individual. Seltzer, Shattuck, Abbeduto, and Greenberg (2004) reported high levels of behavioral problems and mental health comorbidities among adults with autism, and poorer social outcomes as compared to adults with other developmental disabilities. Though a few studies have determined psychosocial outcomes among adults with autism (Engström, Ekström, & Emilsson, 2003; Hofvander et al., 2009; Lord et al., 2005; Whitehouse, Watt, Line, & Bishop, 2009), there is limited understanding of health-related quality of life (HRQOL) among these individuals. HRQOL is a subjective and multidimensional construct that includes the physical, psychological, and social well-being of an individual (Calvert & Freemantle, 2003). Unlike quality of life (QOL), which is a broad outcome measure that encompasses both health and non-health related domains such as economic, environmental, political, and spiritual, HRQOL represents health-related domains that are generally modifiable and responsive to treatments or interventions. In the last decade or so, HRQOL has become a key component of patient health outcome assessment across different clinical settings. Studies across different disease areas have found HRQOL to be a strong predictor of mortality and healthcare utilization, more so than other clinical measures of health (Centers for Disease Control and Prevention (CDC), 2013; Dorr et al., 2006; Mapes et al., 2003; Singh, Nelson, Fink, & Nichol, 2005; Tsai, Chi, Lee, & Chou, 2007).

Poor HRQOL among adults with autism has the potential to complicate their treatment profile by magnifying the psychosocial problems already existent in this group. Thus, there is a critical need for an examination of HRQOL and its determinants among adults with autism. A thorough review of the literature revealed only a handful of studies that have examined QOL/HRQOL among adults with autism (Jennes-Coussens, Magill-Evans, & Koning, 2006; Kamio, Inada, & Koyama, 2013; Kamp-Becker, Schröder, Remschmidt, & Bachmann, 2010; Renty & Roeyers, 2006). In one of the first such studies, Renty and Roeyers (2006) found support characteristics to be a significant predictor of QOL among adults with autism. In their assessment of QOL among young men with Asperger's syndrome, Jennes-Coussens et al. (2006) found lower physical and social health scores among adults with Asperger's syndrome as compared to those without Asperger's syndrome. In another similar study, Kamp-Becker et al. (2010) found adults with autism to have significantly lower physical, psychological, and social health scores as compared to healthy adults. The QOL among adults with autism was found to be influenced by their daily living skills. In a more recent study, Kamio et al. (2013) determined QOL among high-functioning adults with autism. The authors found lower QOL scores in the domains of psychological and social health among adults with autism in comparison to the general adult population. Support received from mothers, age at the time of diagnosis, and presence or absence of comorbid psychiatric conditions and aggressive problems were found to significantly predict QOL of adults with autism.

These studies provide useful information concerning physical and psychosocial health among adults with autism; however, there are some limitations in these studies. First, these studies had small sample sizes, thereby limiting the generalizability of results. The sample size among these studies varied from 12 (Jennes-Coussens et al., 2006) to 154 (Kamio et al., 2013). Second, all these studies were conducted outside the US, which may further limit their generalizability to non-US geographic settings. A thorough review of the literature did not reveal any previous study that has assessed HRQOL among adults with autism residing in the US. Lastly, the role of modifiable factors such as social support and coping in influencing HRQOL among adults with autism is not fully understood. When examining the QOL among adults with autism, Renty and Roeyers (2006) found perceived availability of informal support to influence QOL. Besides the availability of social support, it is also essential to determine the influence of perceived adequacy of informal support from specific sources on the HRQOL of adults with autism. Coping is another factor that has not been studied among adults with autism. Coping represents an individual's cognitive and behavioral attempt at managing stressful events (Folkman & Lazarus, 1980). Coping can be either problem-focused (also referred as 'adaptive coping') or emotion-focused (also referred as 'maladaptive coping'), with the former aimed at dealing with the problem and the latter aimed at regulating the emotions associated with the problem (Folkman & Lazarus, 1980). How adults with autism deal with a diagnosis of autism may have an impact on their HRQOL.

The purpose of this study is to determine HRQOL among adults with autism. The physical and mental HRQOL of adults with autism was compared to that of the general adult US population. Factors predicting physical and mental HRQOL among adults with autism were determined.

2. Methods

2.1. Procedure

Adults with autism who were registered with the Interactive Autism Network (IAN) were approached for participation. Run by the Kennedy Krieger Institute, the IAN maintains an autism registry, and also serves the purpose of fostering relationship between researchers and individuals and families affected with autism (Interactive Autism Network, 2013). From the IAN Research Database, adults with autism: (1) age greater than or equal to 18 years of age; and (2) who had the capacity to place their responses (self-report) with limited or no proxy help, were invited for participation. A cover letter

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