



Factors associated with quality of life in individuals with autism spectrum disorders: A review of literature



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ABSTRACT

This review study was conducted to synthesize the existing research on the level of quality of life (QoL) in individuals with autism spectrum disorders (ASD) and the factors associated with their QoL. A total of 16 studies were included for this review. This study found that (a) the majority of the individuals with ASD had poor QoL; (b) behavior problems and leisure activities were associated with the QoL of the majority of adults with ASD; (c) autism severity, age, behavior problems, social skills, adaptive behavior, education, and comorbid psychiatric conditions were associated with the QoL of the majority of children with ASD. These findings may provide critical information to parents/caregivers of individuals with ASD and practitioners providing services to them.

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1. Introduction

Quality of life (QoL) is defined by the WHO as “individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organization, 1998, p. 11) and this concept suggests that “persons’ physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationships to salient features of the environment” should be considered when measuring QoL (World Health Organization, 1998, p. 11). The concept of QoL not only provides guidance to enhance one’s well-being but also serves as a common language for people to collaborate on making positive changes (Schalock, 2004).

QoL of individuals with autism spectrum disorders (ASD) has been reported by previous studies. Some studies have reported good QoL in individuals with ASD, but others have reported poor QoL in these individuals. For example, Billstedt, Gillberg, and Gillberg (2011) conducted a prospective long-term follow-up study of 120 individuals with ASD from childhood into late adolescence/early adult life and reported that the majority of the individuals with ASD (88%) in their study had average to very good QoL. Gerber, Baud, Giroud, and Carminati (2008) examined QoL of adults with ASD and intellectual disabilities (ID) ($N = 30$, mean age = 39 years) and reported that these individuals had a good QoL. But, Jennes-Coussens, Magill-Evans and Koning (2006) compared QoL of individuals with Asperger syndrome (AS) ($N = 12$, mean age = 20 years) to that of individuals without AS ($N = 13$, mean age = 20 years) and found that the participants with AS rated their QoL lower than the participants without AS. Kuhlthau et al. (2010) measured QoL of children with ASD ($N = 286$, age range = 2–17 years) and reported that QoL of children with ASD was significantly lower than the national norm for a generally healthy population. Limbers, Heffer and Varni (2009) examined QoL of children with AS ($N = 22$, mean age = 9 years) and reported that the QoL of these children was significantly lower than that of healthy children. The inconsistent findings from previous studies seem to suggest that some factors may be associated with QoL of individuals with ASD.

1.1. The factors that may associate with QoL

1.1.1. QoL assessment

Individuals with ASD are characterized by qualitative impairment in social interaction and communication as well as displaying repetitive and stereotyped patterns of behavior and interests (American Psychiatric Association, 2000). Many individuals with ASD have language development delay (Weismer, Lord, & Esler, 2010) and cognitive development delay (Ray-Subramanian, Huai, & Weismer, 2011). Thus, it may not be possible for every individual with ASD to conduct a direct assessment on his/her QoL (Persson, 2000). Therefore, many studies have had their family members or residential staff to evaluate these individuals’ QoL (e.g., Billstedt et al., 2011; Gerber et al., 2008; Kose et al., 2013). However, the results from objective QoL assessments may be different from subjective QoL assessments.

1.1.2. Cognitive and adaptive functioning

Individuals with AS differ from individuals with autistic disorder (AD) in language and cognitive development (American Psychiatric Association, 2000). Individuals with ASD without ID are more likely than individuals with ASD with ID to participate in employment (Chiang, Cheung, Li, & Tsai, 2013). Many individuals with ASD who have limited spoken language skills have behavior problems (Chiang, 2008). Behavior problems may negatively affect QoL of individuals with ASD (Garcia-Villamisar & Dattilo, 2010). Thus, QoL of individuals with ASD may be affected by individual’s cognitive and adaptive functioning.

1.1.3. Age

Adults with ASD have more years of special education and related services experience than do children with ASD but many of the adults with ASD do not have the opportunity to participate in early intervention services, whereas, nowadays

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