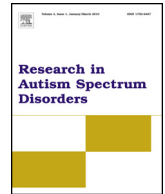




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The quality of life of parents of children with autism spectrum disorder: A systematic review[☆]



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ABSTRACT

Background: Previous research has raised concerns about the quality of life (QoL) of parents of children with autism spectrum disorder (ASD). A better understanding of parental QoL can inform clinicians and policymakers and lead to improved outcomes for both parents and children.

Aims: This review aimed to systematically examine studies measuring the QoL among parents of children with ASD (<18 years) and to investigate its parental, child-related and contextual associated factors.

Methodology: An electronic database search was conducted using Medline, Psycinfo, Embase, CINAHL, Biosis, ASSIA, Social Services Abstracts, Sociological Abstracts and Open grey.

Results: This review indicated poorer QoL among parents of children with ASD compared to parents of typically developing children or to population norms. Variables associated with lower parental QoL within this group included child behavioural difficulties, unemployment, being a mother and lack of social support.

Conclusion: This review verified previous reports on lower QoL among parents of children with ASD and highlighted potential areas of support. Implications for future research, policy and practice are discussed.

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Abbreviations: ASD, autism spectrum disorder; QoL, quality of life.

[☆] *Note:* While preparing this manuscript for publication, this study was published: Dardas and Ahmad (2014). For fathers raising children with autism, do coping strategies mediate or moderate the relationship between parenting stress and quality of life? *Research in Developmental Disabilities*, 36, 620–629.

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1. Introduction

Autism spectrum disorders (ASD) are a group of life-long neurodevelopmental conditions characterised by significant deficits in the social and communication domains and by restrictive, repetitive and ritualistic patterns of behaviour, interests or activities (American Psychiatric Association (APA), 2013). In recent years, there has been a marked increase in ASD prevalence with UK and US population estimates reaching 1.7% and 2.0%, respectively (Blumberg et al., 2013; Russell, Rodgers, Ukoumunne, & Ford, 2014). The increasing levels of ASD stress the need for early identification of the disorder and for targeted interventions in order to improve children's prognosis.

Treatment for ASD typically involves interventions aimed at improving children's adaptive skills and at symptom reduction. In these areas, parent mediated interventions as well as parent training have been receiving increasing support (Diggle & McConachie, 2013; McConachie, Randle, Hammal, & Le Couteur, 2005; Sofronoff, Leslie, & Brown, 2004). Previous studies have demonstrated the effectiveness of parental interventions in improving children's responsiveness, expressive language and functional play as well as in significantly reducing children's behavioural difficulties and sleep problems (Anan, Warner, McGillivray, Chong, & Hines, 2008; Elder, Valcante, Yarandi, White, & Elder, 2005; Kasari, Gulsrud, Wong, Kwon, & Locke, 2010; Siller, Hutman, & Sigman, 2013; Weiskop, Richdale, & Matthews, 2005). Moreover, parental involvement in the treatment of anxiety in children with ASD has also been found effective and is considered a core modification when adapting CBT for children on the spectrum (Moree & Davis, 2010; Sofronoff, Attwood, & Hinton, 2005). Further advantages of parental involvement include increased generalisation and long-term maintenance of treatment gains, as well as cost effectiveness and better allocation of resources (Matson, Mahan, & Matson, 2009; Solomon, Necheles, Ferch, & Bruckman, 2007). Taken together these results suggest that parent mediated interventions could be an efficacious alternative to one-to-one clinician support.

However, the literature suggests that parental capacity to promote the health and overall adjustment of their children may be affected by their own emotional state and wellbeing. For example, parental stress can compromise both parents' and children's coping resources and affect their ability to problem-solve (Friedman & Chase-Lansdale, 2002). Research on the challenges entailed in raising a child with ASD has raised concerns regarding parental wellbeing. Several common factors have been identified in this population including impaired mental and physical health, social isolation and lack of family coherence (Giallo, Wood, Jellott, & Porter, 2013; Silva & Schalock, 2012; Singer & Floyd, 2006; Tsuno, Besset, & Ritchie, 2005).

While previous research in this field has exclusively focused on the negative aspects of caregiving such as stress and caregiving demands (Hastings & Taunt, 2002), a number of recent studies have examined parental QoL in an attempt to provide a more comprehensive assessment of parental adaptation. Quality of life (QoL) is a complex and multidimensional concept that allows for a detailed evaluation of adaptation, both positive and negative, across several domains of functioning. QoL refers to an "individual's perception 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" (WHOQOL Group, 1998, p. 11). QoL measurement has played a paramount role in evaluating the quality and outcome of health care and in influencing the allocation of resources by policymakers (Moons, Budts, & DeGeest, 2006).

Studies examining the QoL of parents of children with ASD have revealed a predominately negative picture. A number of studies have shown the QoL of parents of children with ASD to be lower compared to that of parents of typically developing children. However, the literature lacks a systematic understanding of parental QoL and its associated factors.

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