



Quality of life among parents of children with autistic disorder: A sample from the Arab world



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ABSTRACT

Background: A growing body of research has sought to examine issues associated with the Quality of Life (QoL) of parents of children with Autistic Disorder. However, no studies have examined the QoL of Arab parents whose parenting experience is expected to be substantially different from that of their western counterparts. Therefore, the purposes of this study were: (1) to examine differences in the QoL between fathers and mothers of children with Autistic Disorder in a sample from an Arab country, and (2) to examine the psychosocial correlates of the QoL of Arab parents of children with Autistic Disorder.

Methods: Self-administered questionnaires on parents' QoL, stress, coping strategies, and demographic characteristics were completed by 184 parents of children with Autistic Disorder. The participants were recruited using the convenience sampling design.

Results: Fathers and mothers of children with Autistic Disorder showed no significant differences in their physical, psychological, social, and environmental health. Further, both parents showed almost similar bivariate correlations between the reported QoL levels and their parenting stress, coping strategies, and demographic characteristics.

Conclusion: This is the first study to examine the QoL of parents of children with Autistic Disorder in the Arab world and, in doing so, it highlighted the distinct lack of research in this area. The QoL of Arab parents of children with Autistic Disorder crosses lines with their stress levels, coping strategies, demographic characteristics, and to some extent their cultural context.

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1. Introduction

Throughout life's transitions, parents are considered the most important part of a person's life. Parents can play a central role in children's psychological, social, and academic development. For children with chronic disabilities, studies have found that children's welfare and developmental outcomes can be substantially affected by their parents' mental health (Hart & Kelley, 2006; Pesonen et al., 2008). Autistic Disorder is considered one of the most complex childhood developmental disabilities that can devastatingly affect the children's intellectual, social, and linguistic abilities (American Psychiatric Association (APA), 2000). Recognition of children with Autistic Disorder has increased remarkably

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leaving significant numbers of children who, along with their parents, are in need of extensive support services. Indeed, it has been found that parenting a child with Autistic Disorder can disturb the whole family's life and result in several economic, social, physical and psychological problems (Hartley et al., 2010; Parish, Seltzer, Greenberg, & Floyd, 2004; Shu, 2009). Therefore, it is important to consider the mental health of the parents in the interventions proposed for children with Autistic Disorder.

In response to the wide range of concerns being reported by parents of children with Autistic Disorder, recent research has substantially shifted from the focus on explaining the causality and symptoms of the disorder toward examining issues associated with the experience of parenting children with Autistic Disorder.

The Quality of Life (QoL) has been recently noted as one of the major health concerns for parents following a lifelong complex experience such as raising a child with disability (Mungo, Ruta, Arrigo, & Mazzona, 2007; Shu, 2009; Yamada et al., 2012). Quality of life can be defined as "individuals' 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" (World Health Organization (WHO), 1996, p. 5). The construct of QoL is believed to be a comprehensive outcome measure incorporating an individual's physical health, psychological state, social relationships, and relationships with salient features of the environment (WHO, 1996). In spite of the growing awareness of the need to use the construct of QoL in shaping, directing, delivering, and evaluating support services, little data are available on the impact of raising children with Autistic Disorder on parents' QoL as compared to other chronic disorders.

This study adds to the current research literature in several ways. First, the QoL of individuals has many subjective and objective variables influencing and interacting with its core concepts and as such, cannot be studied independently (Summers et al., 2005; Verdugo, Schalock, Keith, & Stancliffe, 2005). Examples of potential variables that have emerged in the literature and can affect an individual's QoL include perceived stress levels, coping strategies, perceived social support, socio-economic status, and employment status (Lindsay, 2002; Verdugo et al., 2005). However, interactions between these variables for parents of children with Autistic Disorder are not well established, since only a few studies have comprised parental QoL, stress, coping strategies, and demographic characteristics (Manning, Wainwright, & Bennett, 2010; Siman-Tov & Kaniel, 2010). Thus, a better understanding of the interactions between these variables seems essential in order to implement treatments that focus on improving parents' QoL.

Available studies on the relationship between the coping styles adopted by parents of children with Autistic Disorder and its related health outcomes have generally revealed that parents who use avoidance coping strategies tend to be more stressed (Pisula & Kossakowska, 2010; Shu, 2009) and therefore, are prone to poor QoL levels. On the other hand, approach coping strategies such as confrontive coping and problem solving are associated with lower levels of stress and enhanced sense of well-being of parents (Dabrowska & Pisula, 2010; Pottie & Ingram, 2008). Indeed, Hastings et al. (2005) found that parents of children with Autistic Disorder present different coping strategies to address the stress of raising their children. Gray (2006), for example, found seeking social support and formal support the most important strategy for those parents. King and his colleagues (2006) found that they tend to adopt positive meanings to their experiences and struggle to repossess a sense of control over their lives as means to buffer their parenting stress. A not uncommon coping strategy among those parents also was the reliance on distancing strategies which were found to yield both positive and negative outcomes (Abbeduto et al., 2004; Hastings et al., 2005; Sivberg, 2002). Generally, Gray (2006) argued that coping among parents of children with Autistic Disorder is a complex process incorporating a wide range of strategies that change over time and can have various health outcomes.

A second contribution this paper makes is related to the little comparative data available on the QoL between fathers and mothers of children with Autistic Disorder. To the best of our knowledge, only two studies have examined the difference in QoL between fathers and mothers of children with Autistic Disorder (Mungo et al., 2007; Yamada et al., 2012). The results in these studies indicated that mothers tend to have lower QoL levels compared to fathers.

Third, the definition of QoL may vary according to the socio-cultural contexts in which the concept is being utilized and measured. Quality of life definition involves personal and social judgments about what is normal and worthwhile (Verdugo et al., 2005). Therefore, recognition of diversities among cultures is necessary in order to design and conduct a valid and reliable QoL research, as well as accurate cross-cultural programs. Nevertheless, all the studies that have targeted the QoL of parents of children with Autistic Disorder were conducted in Western countries or developed middle-eastern ones. To date, no studies have investigated this concept among parents of children with Autistic Disorder in the Arab world. Arabs are united in a shared culture that is considered substantially different from that of their western counterparts (Retso, 2002). Many cultural, economic, and educational factors can affect the mental health perceptions and practices in the Arab world (Fakhr El-Islam, 2008). On the other hand, in low- and middle-income countries (as in most of the Arab countries), parents who have a child with Autistic Disorder have limited access to professional support services. Coupled with low socio-economic status, low employment status, and poor household conditions, those parents and their families are at increased risk for poor QoL. It has been also reported by the WHO (2011) in its world report of disability that, one of the main challenges for the provision of effective support services for parents of children with Autistic Disorder in the developing countries is the distinct dearth of studies to inform about the impacts of raising children with Autistic Disorder on their parents. Therefore, the purposes of this study were: (1) to examine differences in the QoL between fathers and mothers of children with Autistic Disorder in a sample from the Arab world, and (2) to examine the psychosocial correlates of the QoL of Arab parents of children with Autistic Disorder.

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