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## Correlates of health-related quality of life and the perception of its importance in caregivers of children with autism



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### ABSTRACT

This study aims to investigate the correlates of health-related quality of life (HRQOL) and perceptions of the importance of each HRQOL domain in caregivers of children with autism. Eighty-two caregivers completed the World Health Organization Quality of Life and Parenting Stress Index Short Form to respectively measure the caregivers' HRQOL and parenting stress. The Childhood Autism Rating Scale and the Strength and Difficulties Questionnaire were used to respectively assess severity of autism and children's behavior problems. Results revealed that severity of autism, behavior problems, and parenting stress individually had low to moderate associations with HRQOL. However, all variables considered together, only parental distress (parent-related stress) significantly contributed to the four HRQOL domains. In addition, the physical domain was the most important HRQOL domain to caregivers, and environmental domain, the least. Knowledge of the correlates of HRQOL and the importance of each HRQOL domain could serve as guides for clinicians to improve the HRQOL of caregivers of children with autism by targeting parental distress and focusing on the HRQOL domains perceived as most important by caregivers.

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## 1. Introduction

The health and functioning of children will inevitably affect their caregivers, for children often need a caregiver's assistance to complete their daily activities (Bourke-Taylor, Howi, & Law, 2010). Poor child functioning may increase the caregiver's burden by forcing caregivers to adjust their daily lives to fit their children's special medical and education needs. Caregivers of children with autism who often function poorly in daily activities may experience increased caregiving burden and challenges, which in turn could result in a variety of psychological problems, such as parenting stress (Davis & Carter, 2008), depression, diminished physical health, and most important of all, worse health-related quality of life (HRQOL) (Davis & Carter, 2008; Khanna et al., 2011; Kheir et al., 2012; Shu, 2009).

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HRQOL synthesizes the concept of health and QOL (Donohue, 2004; Khanna et al., 2011). QOL is defined as 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” (The WHOQOL Group, 1998). HRQOL is directly related to an individual’s perception of their health status, which is amenable to healthcare interventions. The World Health Organization (WHO) has described HRQOL as a multidimensional concept and developed a HRQOL assessment, the brief form of the World Health Organization Quality of Life (WHOQOL-BRIEF). The WHOQOL-BRIEF, which comprises physical, psychological, social, and environmental domains (The WHOQOL Group, 1998), is often used in evaluating HRQOL in caregivers of children with autism (Lee et al., 2009; Mugno, Ruta, D’Arrigo, & Mazzone, 2007; Shu, 2009).

There are two important reasons to measure the HRQOL of caregivers of children with autism, both of which are based on the concept of family-centered practice. First, HRQOL is an indicator of caregivers’ adaptation to their children’s disabilities (Allik, Larsson, & Smedje, 2006; Mugno et al., 2007; Yamada et al., 2012). Caregivers who perceive a good HRQOL are considered able to adapt better to the long-term pressure of taking care of children with autism. In contrast, caregivers who perceive a poor HRQOL are considered to have difficulty adapting to their children’s disability. Second, understanding HRQOL could have direct implications on improving the child–parent relationship and quality of care provided to the child. For example, when caregivers have poor psychological and physical health, children are more likely to experience verbal abuse (screaming, yelling, and insults) from their caregivers (Beach et al., 2005). Improving the caregiver’s HRQOL is thus one of the critical goals in interventions for the family of children with autism. Knowing the correlates of HRQOL and thoroughly understanding the caregiver’s perceptions of HRQOL can help health professionals to target interventions on improving the HRQOL of the caregiver.

Child and caregiver characteristics have been found to be correlates of HRQOL in caregivers of children with Autism. As regards child characteristics, a child’s behavior problems and severity of autism can strongly affect caregiver’s HRQOL (Allik et al., 2006; Khanna et al., 2011). Allik et al. (2006) reported that the psychological HRQOL of caregivers was related to child’s behavior problems, such as hyperactivity, and conduct problems. Khanna et al. (2011) found that severity of autism and behavior problems were significant predictors of a caregiver’s psychological and physical HRQOL, respectively. However, the 12-item Short Form Health Survey (SF-12), which was used to examine HRQOL in both studies, targets the impact of illness on the individual’s ability to carry out everyday activities, rather than caregivers’ subjective perception of their quality of life as defined by the WHO (Andrews, Sanderson, & Beard, 1998; Mond, Owen, Hay, Rodgers, & Beumont, 2005; Spitzer et al., 1995). Moreover, the SF-12 comprises only two aspects of HRQOL, physical and psychological health status. Unlike the WHOQOL-BRIEF, it does not consider the caregiver’s perceptions about their social interactions and living environment. The impacts of behavior problems and severity of autism on social and environmental HRQOL remain unknown.

As regards caregiver characteristics, parenting stress could be a potential correlate with the HRQOL of caregivers because parenting stress is often linked to negative outcomes, such as depression, anxiety, and poor HRQOL (Deater-Deckard, 2004). To our knowledge, only one study, by Khanna et al. (2011), has examined the influence of caregiver’s parenting stress on HRQOL. In their study, the total score of the Caregiver Strain Questionnaire, representing the entirety of parenting stress that the caregiver suffered, was used to examine its effect on HRQOL. However, parenting stress is known to encompass three dimensions: parent-related stress, child-related stress, and stress in parent–child interactions (Abidin, 1992; Deater-Deckard, 2004). Different aspects of parenting stress might have different impacts on caregivers’ HRQOL. In considering the entirety of parenting stress, the individual associations between different aspects of parenting stress and HRQOL could be blurred. If clinicians do not understand the interactions between each aspect of parenting stress and HRQOL, they may not be able to focus interventions effectively. Further empirical study is warranted.

In addition to correlates of HRQOL in caregivers of children with autism, in the practice of client-centered health-care, the importance that caregivers assign each HRQOL domain should motivate clinicians to note caregivers’ concerns. Since HRQOL is a multi-dimensional construct (Skevington, Lotfy, & O’Connell, 2004) and caregivers often report poor HRQOL in all domains (Davis & Carter, 2008; Khanna et al., 2011; Kheir et al., 2012; Shu, 2009), it may be wondered which domain is most critical to caregivers. To date, the importance that caregivers assign to each domain of HRQOL is still unknown. Further study is thus warranted.

Our study aimed to (1) examine the correlates of the HRQOL in caregivers of children with autism, including three variables: severity of autism, behavior problems, and parenting stress; and (2) investigate caregiver’s perceptions of the importance of each HRQOL domain. Caregivers’ HRQOL was also compared with that of the general population in Taiwan to validate their poorer HRQOL than the general population such that the wellbeing of caregivers of children with autism should merit the concern of healthcare professionals.

## 2. Method

### 2.1. Participants

From July 2012 to September 2013, children with autism and their caregivers were recruited from two hospitals, two pediatric rehabilitation clinics, and a developmental center in Taipei and Tainan, two cities in Taiwan. Inclusion criteria were (1) children were 3–12 years old; (2) children had a diagnosis of Autistic Disorder based on the diagnostic criteria of the Diagnostic and Statistical Manual of Mental Disorders—Fourth edition, Text Revision (DSM-IV-TR) (American Psychiatric Association, 2000) or the International Statistical Classification of Diseases and Related Health Problems 10th Revision

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