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## Predictors of the health-related quality of life in preschool children with Autism spectrum disorders

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### ABSTRACT

This study was aimed to identify the predictors of health-related quality of life (HRQOL) by considering the caregiver's characteristics such as mental health and parenting stress as well as child characteristics in preschool children with Autism spectrum disorders (ASD). A total of 106 children aged 36–70 months participated in this study. The study indicated that the predictors of HRQOL in children with ASD encompassed not only child but also caregiver characteristics. In particular, good HRQOL on the domains of social and emotional functioning in children with ASD depended upon the caregiver's mental well-being. In summary, the present findings highlight the need for assessment of caregivers' parenting stress and their mental status as well as the predictors of HRQOL in children with ASD. Furthermore, the findings of the study could serve as a guide for clinicians to target at the predictors when providing assessment and intervention for children with ASD to improve their HRQOL.

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## 1. Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder with three core symptoms: impairments in social reciprocity and communication skills, and repetitive and restricted behaviors or interests (American Psychiatric Association, 2000). The estimated prevalence of ASD is 1 in 88 (Centers for Disease Control Prevention, 2014). ASD has a multifaceted impact on children's adaptive functioning, which in turn adversely affect children's quality of life (Chuang et al., 2012; Kuhlthau et al., 2010; Lee, Harrington, Louie, & Newschaffer, 2008; Tseng, Fu, Cermak, Lu, & Shieh, 2011).

Quality of life (QOL) is a multidimensional concept that includes subjective evaluations of an individual's physical, mental and social well-being (WHO, 1998). Health-related quality of life (HRQOL) is the extent to which health impacts an individual's ability to function and his/her perceived well-being in all domains of life (Eiser, Mohay, & Morse, 2000; Ferrans, 2005; Hays, Hahn, & Marshall, 2002; Kuhlthau et al., 2010). HRQOL is multidimensional and well suited for assessing the impact of ASD on QOL (Kuhlthau et al., 2010, 2013; Lee et al., 2008; Tilford et al., 2012).

Despite much research investigating a variety of outcomes in children with ASD, there have been few studies of HRQOL (Limbers, Heffer, & Varni, 2009; Kamp-Becker et al., 2011; Kose et al., 2013; Kuhlthau et al., 2010, 2013; Lee et al., 2008), and

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even fewer with preschool children (Kose et al., 2013; Kuhlthau et al., 2010; Lee et al., 2008). Results of these studies showed that children with ASD had lower HRQOL than children in general populations (Limbers et al., 2009; Kamp-Becker et al., 2011; Kose et al., 2013; Kuhlthau et al., 2010, 2013; Lee et al., 2008). In addition, HRQOL of children with ASD was also lower than children with Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder (ADD/ADHD) (Lee et al., 2008), and children with chronic illness (Kuhlthau et al., 2010).

Exploring factors predictive of HRQOL is crucial to identify intervention aimed at improving HRQOL for children with ASD. However, no studies to date have identified predictors of HRQOL for children with ASD except Kuhlthau et al. (2010, 2013) and Tilford et al. (2012). Kuhlthau et al. (2010, 2013) examined the relationship between HRQOL and child characteristics. Results showed that HRQOL was associated with age, ASD severity, adaptive behaviors, internalizing and externalizing behavioral problems and ASD-related and aberrant behaviors. Tilford et al. (2012) found that HRQOL measures were related to child's adaptive behaviors and cognitive functioning when comparing the sensitivity of two generic HRQOL measures relative to ASD-related conditions and symptoms.

In addition to child characteristics, caregivers' characteristics, such as mental health or parenting stress, have been reported to influence child's HRQOL in children with cerebral palsy, psychiatric disorders as well as typically developing children (Arnaud et al., 2008; Bastiaansen, Koot, & Ferdinand, 2005; Kahn, Brandt, & Whitaker, 2004; Manuel, Naughton, Balkrishnan, Smith, & Koman, 2003; Waters et al., 2000; White-Koning, Arnaud, & Dickinson, 2007; Wiley & Renk, 2007). However, to date, no studies have considered caregiver's characteristics when investigating the predictors of HRQOL in children with ASD.

Moreover, along with changes in expectations as a child grows, the challenges a child faces are also changing (Newman & Newman, 1997). Consequently, the factors influencing HRQOL may not be the same for all ages; for example, social resources are more important to older children than younger ones (Von Rueden, Gosch, Rajmil, Bisegger, & Ravens-Sieberer, 2006). Nevertheless, Kuhlthau et al. (2010) and Tilford et al. (2012) included a wide age range of participants, i.e., from toddlers through adolescents, and their results may not be applicable to children at a specific age, such as preschoolers. There have been no studies as yet investigating the predictors of HRQOL exclusively in preschool children.

Thus, this study aimed to identify the predictors of the HRQOL by considering the caregiver's characteristics such as mental health and parenting stress in addition to child characteristics in preschool children with ASD. Results of this study could inform clinicians' evaluation and intervention planning targeted at the factors to improve their HRQOL at an early stage.

## 2. Method

### 2.1. Participants

Children with ASD were recruited from four developmental centers, three pediatric rehabilitation clinics, one department of child psychiatry and six departments of physical medicine and rehabilitation in general hospitals in northern Taiwan. The inclusion criteria included: (1) Children who were diagnosed with autistic disorder, Asperger disorder, or PDD-NOS by child psychiatrists based on criteria in the DSM-IV-TR. (2) Children aged 3–5 years. (3) Parents or primary caregivers who gave informed consent. (4) Primary caregivers who could communicate in Mandarin or Taiwanese. The exclusion criteria were children with sensory limitations such as blindness, deafness, and severe motor limitations which hindered adequate testing. One hundred and six 3–5-year-old children with ASD were recruited in this study. The demographic information of the 106 children with ASD is shown in Table 1.

### 2.2. Instruments

#### 2.2.1. HRQOL measure

The Chinese version of the TNO-AZL Preschool children Quality of Life (TAPQOL-C) questionnaire (Lee et al., 2005) was used to measure parent's perception of their child's HRQOL. It was designed for children aged from 1 to 5 years, containing 43 items divided into 12 subscales that cover four domains: physical functioning (sleeping, appetite, lung problems, stomach problems, skin problems, motor functioning); social functioning (problem behavior, social functioning); cognitive functioning (communication); and emotional functioning (positive mood, anxiety, and liveliness). The questionnaire focuses on health problems in the past 3 months or the last weeks, and, if problems were present, the well-being in relation to the health problem is assessed. Lower scores of the TAPQOL-C indicate poorer HRQOL. The TAPQOL-C demonstrated good psychometric properties among Taiwanese preschool children (Lee et al., 2005). Coefficient alpha is 0.9 for the total scale and ranges from 0.76 to 0.94 for the four dimensions. The uni-dimensionality of each subscale is confirmed by principal component factor analysis, which lends support to construct validity of the TAPQOL-C.

#### 2.2.2. Child characteristics

The following child characteristics were evaluated: age, gender, age when therapy services were initiated, diagnosis, severity of ASD, cognitive function, communication, emotional and behavioral problems, temperament, sensory processing, and adaptive functioning.

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