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Predictors of Health-Related Quality of Life in Chinese Caregivers of Children With Autism Spectrum Disorders: A Cross-Sectional Study

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A B S T R A C T

The purpose of this study was to identify the predictors of health-related quality of life (HRQOL) among caregivers of children with autism spectrum disorders (ASD) in China. Two hundred and seventy-three caregivers were surveyed using questionnaires on HRQOL, family functioning, coping style, social support, and caregiver burden. Besides socio-demographic characteristics of children with ASD and their caregivers, results demonstrate that family functioning, coping style, social support, caregiver burden are predictors of HRQOL in caregivers of children with ASD, and these predictors correlated with each other. These results indicate that comprehensive intervention, which focuses on improving caregivers' coping strategies, social support (especially from family members and friends) and family functioning, and on releasing caregiver burden, should be provided to caregivers of children with ASD.

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Autism spectrum disorder (ASD) was first identified as a syndrome by Leo Kanner in 1943 (Blacher & Christensen, 2011). ASDs are defined as neurodevelopmental disorders characterized by impairment in communication, social reciprocity, and repetitive-restricted interests and behaviors (American Psychiatric Association, 2000). A worldwide disorder that crosses all racial, ethnic, cultural and social boundaries (Belfer, 2008), the identified prevalence of ASD has increased significantly since 1985 in the USA (CDC, 2012), South Korea (Kim et al., 2011) and Australia (ABS, 2011). This trend also occurred in China (Fan, Jie, & Zou, 2008; Wu, Zhou, & Xu, 2008). Professor Tao first reported four cases of children with ASD in China in 1982, and subsequently, about 1.8 million children with ASD have been reported across the country (Autism-World, 2008).

Studies show that caring for a child with an ASD can be challenging and substantially affects caregivers' health-related quality of life (HRQOL) (Khanna et al., 2011; Kheir et al., 2012; Yamada et al., 2012). HRQOL refers to the physical and mental aspects of health (Testa & Simonson, 1996), which directly correlates with the caregiver's health, and also impacts on the quality of care they provide to children with ASD and their resultant rehabilitation (Beach et al., 2005). Therefore, it is important to identify the predictors of HRQOL and provide effective interventions to caregivers of children with ASD.

In terms of predictors of HRQOL, studies conducted in the USA indicate that coping skills (Zablotsky, Bradshaw, & Stuart, 2013), social support (Zablotsky et al., 2013), family functioning (Johnson, Frenn, Feetham, & Simpson, 2011), parenting stress (Johnson et al., 2011) and autism severity (Khanna et al., 2011; Zablotsky et al., 2013) are associated with HRQOL among caregivers of children with ASD. Cultural contexts should be considered on research of caregivers of children with ASD (Desai, Divan, Wertz, & Patel, 2012). Predictors of HRQOL of caregivers of children with ASD may differ based on social support opportunities and cultural concerns within the country of residence. As demonstrated by Chiu, Yang, Wong, Li, and Li (2013), Chinese caregiving is characterized by a lack of formal support, and cultural concerns as loss of face (*mianzi/lian*) and strong affiliated stigma, which were found to account for caregivers' health. In Chinese culture, *mianzi* (social face) refers to the desire to preserve and maintain one's social image and social worth based on performance and role within an interpersonal context (Mak & Chen, 2006), while *lian* (moral face) is defined as a physical, emotional, social and moral process which is often internalized in Chinese society (Yang & Kleinman, 2008). These cultural concerns can have an adverse effect on the informal support caregivers need. In China, autism rehabilitation centers are mostly privately operated. Previous studies have found that teachers in these autism rehabilitation centers have limited knowledge and several misconceptions regarding autism spectrum disorders (Yang, Guo, & Qian, 2012; Zhang, Li, Mao, Wang, & Geng, 2012). These may cause lack of formal support among caregivers, because teachers in these autism rehabilitation centers are caregivers' main source of formal support. Several studies reported that parents of children with ASD exhibited lower mental health (Liu, Du, Zhao, & Li, 2006) and poorer quality of life (Xie, Liu, & Zhang, 2012; Zhou, Zou,

Heng, Kuang, & Fu, 2010), and were more likely to develop depression and anxiety compared with parents of children with typical development (Guo, Li, & Liu, 2006). Researchers have found that caregivers of children with ASD and the general population only have limited knowledge about autism spectrum disorders in China (Wang, Huang, Xiao, Xie, & Chen, 2009; Wang et al., 2013). In general, this disease has greater impact on caregivers and families of children with ASD in developing counties, such as China, than for those in developed counties, partly because of a lack of knowledge and social support systems (Xiong et al., 2010; Xu, Cheng, Bai, Shi, & Zhang, 2006). However, limited research about the HRQOL and its predictors among caregivers of children with ASD exists in China and hence the main purpose of this study was to investigate the HRQOL in caregivers of children with ASD and identify its predictors.

METHODS

Study Design and Data Collection

This is a cross-sectional study, conducted in 15 autism centers in Hunan Province of China from March 2011 to July 2012. Ethics approval was obtained from the Central South University Human Research Ethics Committee. Written informed consent was obtained from each participant prior to their participation in the study.

All caregivers in the 15 autism centers were recruited by simple cluster sampling. The inclusion criteria were: (a) having a family member (0 to 14 years old) with a diagnosis of ASD according to the *DSM-IV* criteria and *ICD-10* criteria (American Psychiatric Association, 2000; WHO, 1993); (b) being identified as the main caregiver of the child/children with ASD; and (c) being 18 years or older. Caregivers were excluded if they were cognitively impaired, or if they received payment for taking care of children with ASD. Based on the inclusion and exclusion criteria, 280 caregivers of children with ASD were recruited in this study with only seven withdrawing because of privacy considerations. Finally, 273 caregivers were included and completed the questionnaires. The response rate in the study was 97.5%.

Measures

Socio-demographic Variables of Caregivers and Children With ASD

The socio-demographic information collected from participants included: age, gender, educational level, religious belief, marital status, caregiver–child relationship, place of residence, employment status, number of children, family income and caring time (hours used for caring for children with ASD per day). Participants were also asked to answer a personal-health questionnaire to identify their child's age, gender, rehabilitation time, age of diagnosis and payment of medical expenses.

Short Form-36 (SF-36)

The Chinese version of the SF-36 (the 2nd edition) was adopted as a measure of HRQOL (Liu & Huang, 2010). It consists of eight subscales (36 items): physical functioning (PF); physical and emotional roles (RP and RE); body pain (BP); general health (GH); vitality (VT); social functioning (SF); mental health (MH); and one single item dimension on health transition. These domains can be further aggregated into a Physical Component Summary (PCS) and a Mental Component Summary (MCS) by weighting eight domains, both of which are scored from 0 to 100 following a standard algorithm with higher scores representing better HRQOL (Liu & Huang, 2010).This questionnaire is widely used in the Chinese population, and as such demonstrates high reliability and validity (Gong, Zhang, Zhu, Sun, & Feng, 2004; Yang, Wand, Li, & Chen, 2009). In this study, the Cronbach's α for internal consistency was 0.878.

McMaster Family Assessment Device (FAD)

Family functioning was assessed using the FAD (Epstein, Baldwin, & Bishop, 1983). It consists of seven sub-scales with a total of 60

items: problem solving; communication; roles; affective responsiveness; affective involvement; behavior control; and general functioning. All items in the FAD are measured on a four-point Likert scale ranging from 1 (indicates a healthy answer) to 4 (indicates a pathological finding). The scores are calculated by averaging the scores on all items, with higher scores representing greater problems in family functioning. The Chinese version of the FAD has been used in several studies and it shows good reliability and validity (Su & Duan, 2008). In this study, the Cronbach's α for internal consistency was 0.859.

Simplified Coping Style Questionnaire

The simplified coping style questionnaire includes 20 items aimed at measuring Chinese people's coping style (Wang, Wang, & Ma, 2009). The coping styles in this questionnaire were classified into two categories: positive coping styles (12 items) and negative coping styles (8 items). In general, coping serves two functions, dealing with the problem that is causing the emotional distress (problem-focused or active coping) and dealing with the distressing emotions caused by the problem (emotion-focused or passive coping) (Kraaij, Garnefski, & Maes, 2002). Scores range from never (0) to always (3). According to Xie (1998), the alpha coefficient for whole scale, positive coping style and negative coping style was 0.90, 0.89 and 0.78, respectively. In the present study, the Cronbach's α for internal consistency was 0.89.

Multidimensional Scale of Perceived Social Support (MSPSS)

The MSPSS is a self-administered scale which aims to evaluate people' perceived social support from family, friends and significant others (Zimet, Powell, Farley, Werkman, & Berkoff, 1990). It includes three domains with a total of 12 items: support from family (4 items); support from friends (4 items); and support from others (4 items). Items are rated on a seven-point Likert-scale ranging from 1 (very strongly disagree) to 7 (very strongly agree). The total score ranges from 12 to 84 with the higher score suggesting more social support. The Chinese version of the MSPSS (MSPSS-C) is reported to have good reliability and validity (Chou, 2000). A Cronbach's α of 0.815 was obtained for the MSPSS-C in current study.

Caregiver Burden Index (CBI)

The CBI is a 24-item self-administered questionnaire, which is used to assess caregiver burden. The CBI includes five domains of burden: time burden; burden of personal development limitations; physical burden; social burden; and emotional burden. All items are rated on a four-point scale. Higher scores indicate greater caregiver burden. Novak and Guest (1989) reported Cronbach's α values of subscales ranging from 0.76 to 0.96. Good validity and reliability of the Chinese version of CBI for the Chinese population are reported by Chou, Lin, and Chu (2002). Internal consistency, as assessed by Cronbach's alpha was 0.875.

Childhood Autism Rating Scale (CARS)

Severity of autism symptoms was measured using the teacher-completed CARS (Schopler, Reichler, & Renner, 1988), a 15-item behavioral rating scale used to screen for ASD. Items are rated on a scale of 1 (normal) to 4 (severely abnormal). The higher scores indicate the more severe autistic characteristics of the child, with a score of 36 or higher indicating mild to severe autism spectrum disorders (Li, Zhong, Cai, Chen, & Zhou, 2005). The Chinese version of the CARS has strong reliability and validity (Yin, Chen, Luo, & Li, 2011). In this study, Children's primary teachers in rehabilitation centers were surveyed using this scale.

Statistical Analysis

Summary descriptive statistics of caregivers' and recipients' socio-demographic data were counts and percentages for categorical variables, and means and standard deviations (SDs) for continuous