Neuropsychiatric Symptoms, Parenting Stress and Social Support in Chinese Mothers of Children with Autism Spectrum Disorder

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Summary: Although little is known about the current situation regarding autism spectrum disorder (ASD) in mainland China, psychiatric disorders are common among Chinese mothers of preschool children with ASD. Previous studies showed ASD child's behavioral symptoms, maternal anxiety, and maternal depressive symptoms were associated with overall parenting stress in northern China. In the present study, we retrospectively analyzed medical records at the hospital related to neuropsychiatric symptoms, parenting stress and social support in mothers of children with ASD from southern China. A total of 80 mothers of children with ASD were screened. Among them, 34 mothers were in low-functioning ASD group (L-ASD group) and 46 mothers were in high-functioning ASD group (H-ASD group). Identification of the ASD cases was confirmed with a Revised Autism Diagnostic Inventory. Neuropsychiatric symptoms, parenting stress and social support were measured by neuropsychiatric inventory (NPI), parenting stress index short form (PSI-SF), and multi-dimensional scale of perceived social support (MSPSS). Total mean score of the NPI in the L-ASD group was significantly higher than that in the H-ASD group (P<0.01). The subscale scores of NPI, including depression, anxiety, apathy, irritability, agitation, night time behavior disturbances and change in appetite were significantly higher in the L-ASD group than those in the H-ASD group (P<0.01 or P<0.05). Meanwhile, the total PSI-SF scores and the scores of parental distress (PD), parental-child dysfunctional interaction (PCDI) and difficult child (DC) in the L-ASD group were significantly higher than those in the H-ASD group (P<0.01 or P<0.05). The total score of MSPSS was also higher in the L-ASD group than in the H-ASD group (P<0.01). This study goes further to show the neuropsychiatric symptoms and parenting stress are significantly higher in mothers of children with ASD, and more social supports are needed for mothers of children with ASD from southern China, especially for mothers of children with low-functioning ASD.
Key words: autism spectrum disorder; neuropsychiatric symptoms; parenting stress; social support; mothers

Autism spectrum disorders (ASD) comprise a family of developmental disabilities characterized by language development delays, difficulties with social interactions, and repetitive or stereotyped behaviors[1, 2]. Sometimes the syndrome is divided into low-functioning or high-functioning ASD based on intelligence quotient thresholds. Although the mechanism of its pathophysiology is not clear now. Our previous studies[3] showed cortical thickness values in ASD subjects decreased with age. Histological sections showed cortical layering was largely undisturbed, with cell clustering and supernumerary cells found in layer I and the subplate. Greater spine densities in ASD subjects were found predominantly within layer II of each cortical location and within layer V of the temporal lobe. High spine densities were most commonly found in ASD subjects with lower levels of cognitive functioning[4]. Further clinical studies[5] showed serum total bilirubin, neuron-specific enolase and creatine kinase brain band isoenzyme were higher in the low-functioning ASD (L-ASD) group than in the high-functioning ASD (H-ASD) group, while the neonatal behavioral assessment scales scores were lower in the L-ASD group than in the H-ASD group. All these abnormal structures not only help us to understand the pathophysiology of ASD, but also help us to understand the severe behavioral abnormality, which may be related to increased burden of parents to raise ASD children.

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It is well known that ASD has a great impact on the quality of life of patients and their family members that provide long-term health care. Not only the patients but also their caregivers need professional attention and support in order to maintain their own physical and emotional health and well-being. Elevated parenting stress has been observed among mothers of children with ASD in western countries, but little is known about Chinese mothers of children with ASD. Mothering children with ASD results in mother spending more time on daily task as well as managing the disorder. One study[6] from Heilongjiang province in northern China focused on stress experienced in mothers of children with ASD by examining maternal parenting stress. The participants reported elevated parenting stress in mothers of children with ASD as compared with mothers of normal subjects. Meanwhile, mothers' parenting stress was found associated with levels of depression and anxiety, and the patients' behavioral symptoms. Thus, the aim of this study goes further to measure the neuropsychiatric symptoms, parenting stress and social support in mothers of children with different level of ASD from southern China.

1 MATERIALS AND METHODS

1.1 Participants

In this retrospective study, a total of 80 mothers of children with ASD were screened. Among them, 34 mothers were in the L-ASD group and 46 mothers were in the H-ASD group. Identification of the ASD cases was made based upon available medical and psychological records at the hospital from June 2003 to June 2009, and the diagnosis was confirmed with a Revised Autism Diagnostic Inventory[7]. The demographic data including mothers' age, occupation, educational level, marital status, religion status and family income were documented. In addition, the information about the children's gender, age, and educational level were also included. This study was carried out in accordance with the Declaration of Helsinki, and approved by the institutional review boards of the local Bioethics Committee in Zhongnan Hospital of Wuhan University.

1.2 Instruments

Information on neuropsychiatric symptoms was obtained from mothers of children with ASD using the neuropsychiatric inventory (NPI)[8–10]. NPI is used to screen delusions, hallucinations, depression, anxiety, apathy, irritability, euphoria, agitation, disinhibition, aberrant motor behavior, night time behavior disturbances and change in appetite. Based on the NPI, all domains are rated on presence and magnitude of symptoms (frequency×severity). If the answer to this screening question was "no", then no further questions were asked. If the answer was "yes", then sub-questions were asked and ratings of the frequency and severity of the behavior were made by the caregiver based on scales with anchor points (frequency: 1=occasionally, 2=often, 3=frequently, 4=very frequently; severity: 1=mild, 2=moderate, 3=severe). The maximum score is 12 per domain, for a given domain with significant symptoms occurring at (frequency×severity) scores ≥4. A global score for the NPI was generated by summing the total scores of the individual subscales. The total NPI scores range from 0 to 144, with higher scores indicating greater behavioral problem. The Chinese version of NPI was shown to be a reliable and valid tool to assess neuropsychiatric syndromes in Chinese subjects[11, 12].

The parenting stress index short form (PSI-SF) was derived from the full-length PSI[13]. The PSI-SF is a self-report instrument designed to identify parent-child systems under stress. It was constructed for parents of children who need special care and support, such as children who suffer from ASD. PSI-SF measures the stress level of the mothers with a child from one month to twelve years. The range of values for each item on the index is from 1 (strongly disagree) to 5 (strongly agree). Normal ranges have been reported to be within the 15th to the 80th percentiles. High scores are considered to be above the 85th percentile. The subscales in the instrument are described as parental distress (PD, distress experienced in parenting); parental-child dysfunctional interaction (P-CDI, perception that child does not meet parent's expectations); and difficult child (DC, behavioral characteristics that make the child easy or difficult to manage). The instrument evaluates whether subjects may be feigning that they are functioning better than they actually are. Higher scores indicate a greater degree of stress. The PSI-SF has been translated into Chinese and previously used in Chinese subjects, and tested to have good reliability and construct validity[14–16].

The multi-dimensional scale of perceived social support (MSPSS) was developed and revised by Zimet, and used to measure the perceived social support[17]. It is a validated 12-item instrument used to assess perceptions of the participants about support from family, friends and significant others, and measured with a seven-point scale (1=very strongly disagree to 7=very strongly agree). Sample items include "My family is willing to help me make decisions" (4 items on family); "I can count on my friends when things go wrong" (4 items on friends); and "There is a special person with whom I can share joys and sorrows" (4 items on significant others). For each item, participants choose the response from the seven options that best represents his/her experiences. Scoring is conducted by adding up all 12 items to get a total score. The potential range of scores is from 12 to 84, with a middle range score being 48. Calculating scores for each of the three factor groups provides data about one's source of

support. Higher scores indicate greater perceived social support. Reliability and validity of the Chinese version of this scale have been demonstrated in a number of studies[18, 19].

1.3 Statistical Analysis

All data were expressed as the mean±standard deviation (SD) or *n* (%). Group differences were analyzed with SPSS 11 for Windows with a significant level set at $P<0.05$.

2 RESULTS

2.1 Baseline Characteristics between Two ASD Groups

The demographic data between the H-ASD group and the L-ASD group are presented in table 1. There were no significant differences in mothers' age, occupation, educational level, marital status, religion status and family income between the two groups ($P>0.05$). All mothers were married. Nobody had a deceased spouse or was remarried. Most of the primary caregivers were mothers.

2.2 Comparison of NPI Total Scores and Subscale Scores between Two ASD Groups

Table 2 shows the total mean scores of the NPI in the L-ASD group were significantly higher than those in the H-ASD group ($P<0.01$). The subscale scores of NPI, including depression, anxiety, apathy, irritability, agitation, night time behavior disturbances and change in appetite were significantly higher in the L-ASD group than in the H-ASD group ($P<0.01$ or $P<0.05$).

2.3 Comparison of PSI-SF Scores and MSPSS Scores between Two ASD Groups

Table 3 shows the total PSI-SF mean scores and the subscores of PD, P-CDI and DC in the L-ASD group were significantly higher than those in the H-ASD group ($P<0.01$ or $P<0.05$). The total mean scores derived from the MSPSS questionnaire were also significantly higher in the L-ASD group than in the H-ASD group ($P<0.01$). Interestingly, the mean scores

Table 1 Baseline characteristics between two ASD groups (mean±SD) [*n* (%)]

Characteristics	H-ASD group	L-ASD group	*P* value
Mothers information			
Age (years)	31.52±4.26	32.28±4.62	> 0.05
Employment			
Having a job	26 (56.5)	19 (55.9)	> 0.05
Jobless	20 (43.5)	15 (44.1)	> 0.05
Education level			
Junior school	10 (21.7)	8 (23.5)	> 0.05
Senior school	13 (28.3)	10 (29.4)	> 0.05
College	23 (50.0)	16 (47.1)	> 0.05
Married status	46 (100.0)	34 (100.0)	> 0.05
Religion status			
Yes	6 (13.0)	4 (11.8)	> 0.05
No	40 (87.0)	30 (88.2)	> 0.05
Family income			
<3000 RMB/month	16 (34.8)	12 (35.3)	> 0.05
3000–<5000 RMB/month	18 (39.1)	14 (41.2)	> 0.05
5000–10000 RMB/month	8 (17.4)	5 (14.7)	> 0.05
>10000 RMB/month	4 (8.7)	3 (8.8)	> 0.05
Primary caregiver			
Mother	32 (69.6)	24 (70.6)	> 0.05
Father	4 (8.7)	2 (5.9)	> 0.05
Others	10 (21.7)	8 (23.5)	> 0.05
Children information			
Gender			
Boy	24 (52.2)	18 (52.9)	> 0.05
Girl	22 (47.8)	16 (47.1)	> 0.05
Age			
<3 years	10 (21.7)	7 (20.6)	> 0.05
3–6 years	28 (60.9)	20 (58.9)	> 0.05
>6 years	8 (17.4)	7 (20.5)	> 0.05
Education level			
None	38 (82.6)	30 (88.2)	> 0.05
Nursery school	3 (6.5)	2 (5.9)	> 0.05
Primary school	3 (6.5)	2 (5.9)	> 0.05
Middle school	2 (4.4)	0 (0.0)	< 0.05

Table 2 NPI total scores and subscale scores between two ASD groups (mean±SD)

	H-ASD group	L-ASD group	*P* value
Delusions	0.00±0.00	0.00±0.00	>0.05
Hallucinations	0.00±0.00	0.00±0.00	>0.05
Depression	6.34±2.22	9.86±3.71	<0.01
Anxiety	6.57±3.43	10.79±3.82	<0.01
Apathy	6.18±3.08	10.25±3.54	<0.01
Irritability	7.23±2.92	11.98±3.26	<0.01
Euphoria	0.00±0.00	0.00±0.00	>0.05
Agitation	5.16±2.14	9.72±4.03	<0.01
Disinhibition	0.00±0.00	0.00±0.00	>0.05
Aberrant motor behavior	0.00±0.00	0.00±0.00	>0.05
Night time behavior disturbances	7.52±3.05	10.34±4.47	<0.05
Change in appetite	5.64±2.29	7.94±2.98	<0.05
Total scores	47.64±15.36	68.83±19.78	<0.01

Table 3 Total PSI-SF scores and MSPSS scores between two ASD groups (mean±SD)

	H-ASD group	L-ASD group	*P* value
PD	33.64±9.06	50.37±12.66	<0.01
P-CDI	40.58±11.69	48.55±14.87	<0.05
DC	38.62±10.73	52.64±15.35	<0.01
Total PSI-SF	98.27±25.38	126.58±30.47	<0.01
Total MSPSS	60.83±17.35	79.24±21.14	<0.01

PSI-SF: parenting stress index short form; PD: parenting distress; P-CDI: parental-child dysfunctional interaction; DC: difficult child; MSPSS: multi-dimensional scale of perceived social support; SD: standard deviation

for family, friends and other significant individuals were very similar and showed no significant difference (data no shown).

3 DISCUSSION

There are no reliable estimates of the prevalence of ASD in China. Pooled prevalence of childhood ASD was 11.8 per 10 000 individuals in mainland China[20]. The reported prevalence of ASD varied substantially by gender, location of residence, date of publication, and source of the sample[21]. Up to now, there is not special treatment for ASD, and the pathophysiology mechanism of ASD is still unclear. A population-based cross-sectional survey[22] conducted in the Chinese community showed only 57.8% of the respondents could recognize the ASD. Recognition of ASD depended on gender, residing areas, age and educational levels. With respect to the attitudes towards mental health service use for ASD, 84.6% chose to visit a health organization for treatment; 68.2% made the choice of consulting a psychotherapist. Another survey[23] studied the knowledge and attitudes about ASD in Chinese preschool teachers; 84% of participants answered correctly more than half of the questionnaire items assessing understanding of typical child development; in contrast, 83% provided inaccurate responses to more than half of the questionnaire items assessing knowledge of ASD. Knowledge of ASD was associated with geographic region, education level and school type of the participants. These results showed there is a large room for improvement in awareness about ASD in Chinese communities and preschool teachers.

Young mothers with additional needs experience lower quality of life and higher life stress than young mothers of normal children. These adverse effects are stronger in the presence of ASD diagnosis. Parents of children with ASD from two Chinese cities, Beijing and Shenyang experienced more stress and used planning as a coping strategy to a greater degree than parents of children with other developmental disabilities, which is fairly consistent with levels of stress reported in research from western countries[24]. A cross-sectional study[25] conducted in Hunan province of China demonstrated that family functioning, coping style, social support, caregiver burden are predictors of health-related quality of life in caregivers of children with ASD. Meanwhile, parents of ASD children are faced with great financial problems, which is partly due to the under-developed healthcare and education system for ASD children[26, 27]. One previous investigation conducted in Beijing, China in 2011 showed that the raising burden of children with ASD was 19582.4 RMB/year, higher than children with physical disability (16410.1 RMB/year) and children with mental disability (6391.0 RMB/year) as compared with normal children[28]. Parents with higher household incomes may have better knowledge of behavior management through both education and receipts of ASD services. In this study, most of family income was

less than 5000 RMB/month.

Mothers raising young children with ASD face unique caregiving challenges due to difficulties in the daily management of the child's behavioral and emotional symptoms, and the burden of coordinating various specialized services. A cross-sectional study[29] from Hong Kong evaluated the prevalence of affective disorders among mothers of preschool children diagnosed with ASD. The results showed the point prevalence of affective disorders was 29.8%, and the point prevalence of major depressive disorders, adjustment disorders, anxiety disorders, and bipolar affective disorders was 14.9%, 10.7%, 3.3% and 0.8%, respectively. A higher level of disruptive and self-absorbed behaviors in the children, a higher level of accompanying stigma, and a history of psychiatric disorders were independently associated with maternal affective disorders. The perceived stigma and perceived caregiving burden were thought to be predictors of mothers' marital satisfaction[30]. One previous study from Heilongjiang province of China[6] reported elevated parenting stress in northern Chinese mothers of children with ASD as compared with normal subjects. Chinese mothers appeared to be more pessimistic about their children. They often face lots of challenges, including the severe shortage of trained professionals and public educational placement for their children; the added financial burden associated with training and rehabilitation service is not publicly found in China. Research data from Massachusetts city in USA showed that for mothers of toddlers with ASD, lower levels of emotion-focused coping and higher levels of problem-focused coping were generally associated with better maternal well-being; for mothers of adolescents with ASD, coping often acted as a buffer when ASD symptoms were high[31]. In comparison to parents of normal children, parents of autistic children show an inclination to report higher family stress. Research data from Iran and Unite State and United Kingdom aimed to compare the mental health of mothers of children with ASD and those of control group. The results showed that significant differences exist in mental health and anxiety/depression between mothers of children with ASD and control group[32–34]. This study firstly showed total scores of the NPI and the subscale scores of depression, anxiety, apathy, irritability, agitation, night time behavior disturbances and change in appetite in the L-ASD group were higher than those in the H-ASD group. Also, the scores of PSI-SF, including PD, P-CDI and DC, and the total scores of the MSPSS in the L-ASD group were also higher. These results suggest that Chinese mothers of children with L-ASD are experiencing higher stress levels, so high degree of social support is needed for these mothers of children with ASD. This study suggested that the mother's stress increases as the severity of a child's ASD increases.

In China, as an eastern society, mothers are mainly responsible for raising children at home. Mothers are more concerned than fathers about the psychological and behavioral problems of autistic children. The literature on the situation of the healthcare system and educational services for children with ASD in China was profoundly limited. Insufficient knowledge about ASD and inappropriate attitudes towards mental health service use may impede the efforts of early identification and intervention for ASD in China. Health education and promotion, and greater teacher training and instruction are needed to improve people's knowledge about ASD and available mental health services. Recently, Green *et al*[35] reported the adapted Video Interaction to Promote Positive Parenting intervention increased the primary outcome of infant attentiveness to parent, reduced the secondary outcomes of ASD-risk behaviors, increased parental non-directiveness, improved attention disengagement, and improved parent-rated infant adaptive function. They found these intervention effect reduced the risk for later ASD. A multidisciplinary parent education program[36] designed for caregivers of children with ASD showed positive effects on caregivers' health-related quality of life, including the mental health-related quality of life, family functioning, self-efficacy and positive coping style[37, 38]. Unfortunately, parents of child with ASD used more avoidance strategies and less social support-seeking strategies than those of normal children; adequate schooling is often unavailable for children with ASD in China, in part because preschool teachers lack the necessary knowledge and skills to teach these ASD populations. Meanwhile, the cost of interventions and treatment for children with ASD is often not covered by insurance, and parents often pay out of pocket. Thus, greater teacher training and instruction is needed for ASD children, and government support may play an important role in reducing parenting stress for Chinese ASD family.

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Conflict of Interest Statement

The authors declare that there are no conflicts of interest.

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