

Social support among families raising children with autism spectrum disorder

(overview essay)

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Abstract: *This study examined the social support in families who were raising children with autism spectrum disorder (ASD). A total of 172 caregivers parenting a child with ASD from Sichuan province in China were investigated by the Social Support Rating Scale (SSRS). Results indicated that the caregivers had low levels of social support and its sub-domains, including subjective support, objective support, and utilization of support. Caregivers' marital status, educational level, employment status, place of residence, family income, income and expenditure situation, and children's severity level of autism were significantly associated with how families perceived their social support.*

Keywords: *families, caregivers, autism spectrum disorder, social support*

1 Introduction

Autism spectrum disorder (ASD) is characterized by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour and interests (World Health Organization, 2018). Due to its complex and heterogeneous nature, a child diagnosed with ASD may represent a constant source of stress on the family unit (Higgins, Bailey, Pearce, 2005). One factor that has been shown to reduce the negative psychological effects of raising a child with ASD as well as other disabilities is social support (Ekas, Lickenbrock, Whitman, 2010). Social support refers to the perceived or actual assistance that an individual receives from another person or institution and can be in the form of either physical and instrumental assistance or emotional and psychological support (Boyd, 2002). Examples of social support include support from one's spouse, extended one can engage in recreational activities; as well as support from community programs, professional help, and the

availability of services and programs geared toward families with a disabled child (Siklos, Kerns, 2006). Social support perceived by parents of children with ASD was found to be negatively related to financial, social, emotional, and physical burden (Mak, Kwok, 2010), and associated with increased optimism and maternal outcomes (Ekas, Lickenbrock, Whitman, 2010). In other words, families that received social support exhibited healthier adaptation to having a child with ASD (Siklos, Kerns, 2006). However, previous surveys in China reported that the overall social support for families of children with ASD was limited (Ni, Su, 2012; Zeng, 2017). As social support is necessary for families to deal with the intense effects of autism (Lu, Yang, Skora, et al., 2015), and parents' beliefs about receiving adequate social support for themselves and their child have been shown to be very important for successful family adaptation (Siklos, Kerns, 2006), it's imperative to further identify social support and the concepts that influence the social support in caregivers of children with ASD to develop appropriate treatments.

Boyd's review (2002) showed that parent and child characteristics played roles in parents' decision to seek out and use social support. It's likely that an individual's social and cultural context determine availability and use of social support (Singh, Ghosh, Nandi, 2017). Giving Chinese parents experience different social, spiritual, cultural, physical, and personal contexts (Lu, Yang, Skora, et al., 2015), it's particularly important to examine Chinese group in order to equip them with to best care for their children with ASD. However, very limited research so far on social support and its influencing factors among families raising children with ASD exists in China. To the best of our knowledge, only in a study conducted by Xiong and Sun (2014), they found the professional rehabilitation materials and educational support for families of children with ASD were relatively limited, and the main influencing factors were parents' educational level, family residence and economic level. Understanding more about this issue would help determine specialized services tailored for this population. Thus, the present research aimed to identify the social support in a sample of Chinese families and explore the relationship of the child and family characteristics with the social support.

2 Methods

2.1 Participants

The study included a sample of 172 key persons raising a child with ASD under 18 years old in a family recruited from special education schools in Sichuan province, southwest China. As presented in Table 1, the majority of children were male (68.40%), with the age ranged between 0 and 17 years and a mean age being 9.71 years ($SD = 2.936$), and most were described as having moderate or severe

levels of autism (76.50%). Regarding caregiver characteristics, most were married or living with a partner (85.30%), and many had only a senior high school degree or less (65.70%), and nearly half were unemployed (46.70%). In terms of the family characteristics, more than half lived in cities (51.20%), and many had family income less than 4000 RMB (about 580 USD) per month (66.70%). So nearly half of families could just make ends meet (41.90%), while a number of families couldn't (38.40%).

Table 1: *Participant Families Demographics (n = 172)*

Variable	n	%
Child's gender		
Male	117	68.40
Female	54	31.60
Child's age		
Aged 6 and under	18	10.50
Aged 7~14	141	82.50
Aged 15~17	12	7.00
Child's severity level		
Mild	28	16.50
Moderate	62	36.50
Severe	68	40.00
Very severe	12	7.30
Caregiver's marital status		
Divorced, separated, or widowed	25	14.70
Married, or living with a partner	145	85.30
Caregiver's educational level		
Primary school or less	48	27.90
Junior school	34	19.80
Senior high school	31	18.00
Junior college	27	15.70
Bachelor degree or above	32	18.60
Caregiver's employment status		
Unemployment	79	46.70
Job-waiting	13	7.70
Part-time job	16	9.50
Full-time job	61	36.10
Place of residence		
Village	49	28.50
Town	35	20.30
City	88	51.20

Table 1 – continue

Variable	n	%
Monthly income		
≤ 2000 RMB	48	28.10
2001~4000 RMB	66	38.60
4001~6000 RMB	19	11.10
6001~8000 RMB	14	8.20
8001~10000 RMB	13	7.60
≥ 10001RMB	11	6.40
Income and expenditure situation		
Can't make ends meet	66	38.40
Make ends meet	72	41.90
Income outweighs expenditure	34	19.80

Note: Numbers in cells might not add up to 172 due to missing data.

2.2 Procedure

The current study focused on the key person in families raising a child with ASD. The study followed the age criteria set by UNESCO that defined children as the period from birth to 18 years old. So the caregiver raising a child with ASD under 18 years old in a family had been recruited from special education schools in Sichuan province. Convenience sampling was used in the present study. Each recruited family received a letter explained the purpose of the study and stated that participation was voluntary and the family's information would be kept confidential. If the family agreed to participate in, the key person was asked to fill out the questionnaires on behalf of the family.

2.3 Measure

Study questionnaires included items on child and family characteristics and social support. In a brief demographic questionnaire, child's gender, age, and severity level, caregiver's marital status, educational level, employment status, place of residence, monthly income, and income and expenditure situation were collected. Then, social support of families of children with ASD was measured with the Social Support Rating Scale (SSRS). This scale was developed by Xiao (1994). It is composed of 10 items, including three dimensions of subjective support (4 items), objective support (3 items) and utilization of support (3 items). Subjective support refers to emotional or other support experienced by individuals, namely the individuals' emotional experience and satisfaction of being respected, supported, and understood by society. Objective support means the perceived visible or actual support, including the direct assistance and the existence of social networks and groups. The utilization of support

refers to the degree individuals make use of both subjective and objective support (Xiao, 1994). Higher scores indicate more social support, subjective support, objective support, and better utilization of support. Social support scores are classified as low (≤ 44) and high (> 44); subjective support scores are defined as low (≤ 24) and high (> 24); objective support scores are categorized as low (≤ 13) and high (> 13); and utilization of support are defined as low (≤ 9) and high (> 9) (Dai et al., 2016). The scale has been widely used, with good reliability and validity (Liu, 2013). In this study, the Cronbach alpha coefficient of the scale was 0.704.

2.4 Statistical analysis

Data were analyzed using IBM SPSS version 22.0. The reliability of the scale was determined firstly, descriptive statistics of the demographic variables and the score of the scale were then conducted. To explore the differences in the score of social support between child's genders and caregiver's marital status, independent t-tests were conducted. The one-way ANOVAs were used to determine if there were statistically significant differences in the score of social support among child's ages, severity levels, educational levels, employment status, places of residence, monthly income, and income and expenditure situations. Besides, Spearman correlations were calculated to examine the associations between demographic variables and social support. A p-value of < 0.05 was considered statistically significant.

3 Result

First, the descriptive statistics of the families' social support were presented. As reported in Table 2, the total score of social support for families of children with ASD was 34.68 (SD = 8.88), indicating the caregivers received low level of social support. As for the sub-domains of social support, families had low levels of subjective support (M = 20.46, SD = 5.74), objective support (M=7.51, SD=3.36), and utilization of support (M = 6.70, SD = 2.02).

Table 2: *Descriptive statistics of social support and its dimensions*

Dimensions	M (SD)
Objective support	7.51 (3.36)
Subjective support	20.46 (5.74)
Utilization of support	6.70 (2.02)
Overall social support	34.68 (8.88)

Note: M = mean; SD = standard deviation

The results of the independent *t* tests and the one-way ANOVAs showed that no significant differences were observed on the scores of social support in child's gender and age, caregivers' marital status, and place of residence (*ps* > 0.05), but there existed significant differences in child's severity level, caregiver's educational level and employment status, monthly income, and income and expenditure situation (*ps* < 0.01) (see Table 3).

Table 3: *Score comparison on overall social support in different demographic variables*

Demographic variables	Social support M (SD)	F or t	p
Child's gender			
Male	34.50 (8.94)	-0.220	0.826
Female	34.83 (8.72)		
Child's age			
Aged 6 and under	36.94 (12.33)	0.961	0.385
Aged 7~14	34.18 (8.46)		
Aged 15~17	36.25 (7.45)		
Child's severity level			
Mild	38.18 (8.24)	4.206	0.007
Moderate	36.20 (9.89)		
Severe	32.38 (7.70)		
Very severe	31.75 (6.23)		
Caregiver's marital status			
Divorced, separated, or widowed	31.56 (11.41)	1.598	0.121
Married, or living with a partner	35.37 (8.23)		
Caregiver's educational level			
Primary school or below	30.98 (8.46)	4.723	0.001
Junior school	34.13 (8.27)		
Senior high school	34.57 (9.44)		
Junior college	38.33 (8.73)		
Bachelor degree or above	38.03 (7.58)		
Caregiver's employment status			
Unemployment	30.64 (7.06)	11.892	< 0.001
Job-waiting	38.92 (8.68)		
Part-time job	39.06 (10.87)		
Full-time job	37.77 (8.35)		
Place of residence			
Village	32.65 (9.60)	2.914	0.057
Town	33.66 (6.83)		
City	36.27 (8.99)		

Table 3 – *continue*

Demographic variables	Social support M (SD)	F or t	p
Monthly income			
≤ 2000 RMB	30.43 (7.64)	5.074	< 0.001
2001~4000 RMB	34.52 (9.78)		
4001~6000 RMB	37.63 (8.16)		
6001~8000 RMB	40.38 (5.69)		
8001~10000 RMB	38.62 (7.24)		
≥ 10001 RMB	38.18 (6.11)		
Income and expenditure situation			
Can't make ends meet	30.69 (7.96)	12.364	< 0.001
Make ends meet	37.51 (8.43)		
Income outweighs expenditure	36.58 (8.82)		

Note: M = mean; SD = standard deviation; F = Fisher's ratio; t = t statistic; p = p-value. Independent t-tests were conducted for the score comparison of social support between child's genders, and caregiver's marital status, while the one-way ANOVAs were conducted for the score comparison among child's ages, severity levels, educational levels, employment status, places of residence, monthly income, and income and expenditure situations.

When considering the correlations between child related variables and social support, child's severity level showed statistically significant negative association with overall social support ($r = -0.261$, $p < 0.01$), which means that a more severe autism was associated with a lower level of social support. When looking at the correlations between family related variables and social support, caregiver's marital status, educational level, employment status, place of residence, monthly income, and income and expenditure situation all showed statistically significant positive associations with overall social support ($r = 0.195$ – 0.396 , $ps < 0.05$) (see Table 4).

Table 4: *Correlations between demographic variables and social support*

	Objective support	Subjective support	Utilization of support	Overall social support
Child's gender	-0.080	0.066	-0.036	-0.005
Child's age	-0.073	-0.017	0.058	-0.012
Child's severity level	-0.101	-0.310***	-0.129	-0.261**
Caregiver's marital status	0.042	0.225**	0.077	0.195*
Caregiver's educational level	0.131	0.307***	0.346***	0.350***
Caregiver's employment status	0.187*	0.382***	0.281***	0.393***
Place of residence	0.111	0.117	0.295***	0.206**
Monthly income	0.208**	0.341***	0.282***	0.396***
Income and expenditure situation	0.129	0.321***	0.218**	0.343***

Note: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

4 Discussion

Despite a large literature detailing social support among Western families having children with ASD, limited research has examined this issue in Chinese context. The objective of this study was to identify the social support in Chinese families raising a child with ASD. The findings suggested that families had low levels of social support, subjective support, objective support, and utilization of support. This is consistent with previous reports of limited social support (Ni, Su, 2012; Wu, 2010; Zeng, 2017; Huang, Liu, 2006). Siklos and Kerns (2006) also found the parents of children with ASD perceived less satisfaction with the support. ASD, a lifelong developmental disorder, will pose unique and long-term challenges for each member of the family (Lin, Orsmond, Coster, Cohn, 2011). However, the understanding and research on autism started relatively late in China, the social support network provided by country, society, and other NGOs was inadequate (Ban, Sun, 2017). Families' needs for continuous social resources (Wang, 2011) and the insufficient support (Huang, Liu, 2006) might lead to the perceived inadequacy of social support in this study. Research indicating subjective support was more important than objective support (Xu, Chen, Ma, 2018), so future interventions should not only enhance families' support networks but also help them recognize and reduce the exposure to negative support (Smith, Greenberg, Seltzer, 2012) and increase their sense of being supported (Benson, 2012).

Cai, Li, and Zhou (2010) conducted a survey and reported that when there was difficulty in educating child, 79% of families turned to teachers for help, 65% to family members, 40% to parents of children with the same disorder, 31% to friends, colleagues, and relatives, 14% to government agencies, and less than 8% to the media and community personnel. It can be seen that family members were more dependent on the support and help of family members and teachers, which may reflect that families in this study had a lower utilization of support. Chinese parents may intend to avoid seeking support from people outside the family when having a child with disabilities (Lin, Orsmond, Coster, et al., 2011), because Chinese socio-political context makes caregivers of children with ASD have to deal with stigma (Chiu, Yang, Wong, et al., 2013). The stigma that comes with disability may impact on access and availability of social support (Singh, GhoshS, Nandi, 2017). Besides, Taoist philosophy of "do-nothing" approach that emphasizes adapting oneself to the environment through self-cultivation and allowing fate to take its course (Lin, Orsmond, Coster, et al., 2011) may also lead to caregivers isolated from the society and reluctant to seek help from outside supports and resources. Since the strongest indicator of healthy adaptation and coping in the family was the amount of perceived support (Bristol, 1984), there's a great need to strengthen the social support for Chinese families of children with ASD, especially, to help them learn how to use available supportive resources.

As social support was an integral coping resource in the caregiving stress and adaptation process (Singh, GhoshS, Nandi, 2017), another objective of the current study was to explore the relationships between child and family related variables and the caregivers' social support. The study first examined the effect of child's characteristics, and the child's gender, age, and severity level of autism were considered. The significant difference was only found in social support among different severity levels of autism. And the negative association of child's severity level of autism with caregiver's social support indicated a more severe autism was associated with a lower level of social support. This may be due to the fact that children with autism who have more severe limitations may increase the caregiver's burden by forcing caregivers to adjust their daily lives to fit their children's special medical and education needs (Tung, Huang, Tseng, et al., 2014), and place a greater degree of stress and external pressure on families to seek social support to help them address the child's behavior problems (Boyd, 2002). This calls for the educational programs with the professional information that families need to successfully adapt to having a child with ASD (Siklos, Kerns, 2006).

This study also examined the impact of caregiver's marital status, education level, and employment status on social support. The results showed that there were significant differences on the scores of social support in caregiver's educational level and employment status. And all caregiver characteristics (i.e., caregiver's marital status, educational level, and employment status in this study) showed statistically significant associations with social support. The positive relations mean a more satisfied marital, educational, and employment status was associated with a higher level of social support. These findings lend support to Xiong and Sun's (2014) report that parents' education level and employment status influenced their social support. Xu, Chen, and Ma (2018) also evidenced that women with a higher education level could experience more objective support and higher support availability. Families of children with ASD have the greatest difficulty in raising child and bearing the greatest pressure compared with those of other disabled children (Guan, Yan, Deng, 2015). So the higher the degree of education parents received, the more active way they would choose to deal with the problems while educating children (Huang, Liu, 2006). In addition, a more satisfied marital status and more regular work would empower families to seek and use support.

The study explored the impact of place of residence, monthly income, and income and expenditure situation on social support as well. The results showed that there were significant differences on the scores of social support in family income and income and expenditure situation. In addition, place of residence, family income, and income and expenditure situation all showed statistically significant positive associations with social support. It means family's socioeconomic status was the influencing factor contributing to social support. The finding is similar to Xiong and Sun's (2014)

survey that education resources were relatively abundant in big cities but insufficient in small towns and rural areas. Families with high socioeconomic status had more resources at their disposal than low-income families to overcome the challenging problems posed by children's disabilities (Turnbull, Turnbull, 2001). Thus, families with more socioeconomic resources would experience more social support.

There are some limitations that need to be addressed. First, this study only selected the participants in Sichuan province of China (economy less-developed region), which might limit the generalizability of the research findings. Further studies should include the sample in multiple regions. Second, caregivers of children under 18 years old were recruited in this study. Since the caregivers' experiences might vary by the age of the child (Singh, GhoshS, Nandi, 2017), it's worthy to further explore how caregivers' social support vary by the age of the children with ASD. Finally, numerous factors contributed to the social support besides the child and family related variables, so it will be important for future studies to consider other possible factors, such as social and cultural context (Singh, GhoshS, Nandi, 2017), and the caregivers' personality (Boyd, 2002).

Despite these limitations, this study has practical implications. Social services and programs are very important for the successful adaptation of the family of a child with ASD. The social support in families raising children with ASD in the present study need to be improved. We should not only consider the number of supports but also the quality (Siklos, Kerns, 2006). The services provided should respond to the needs identified by the families (Donovan, 1988). As Weiss, Robinson, Fung, et al. (2013) mentioned, the type and quality of support offered, the person providing the assistance, and contextual issues, may all play roles in determining whether parents perceive support as beneficial. Practitioners should focus on informal social networks of families of children with ASD to help them to be available and offer meaningful support.

5 Conclusion

The current study suggested that families raising a child with ASD had low levels of social support and its sub-domains, including subjective support, objective support, and utilization of support. Caregiver's marital status, educational level, employment status, place of residence, family income, income and expenditure situation, and children's severity level of autism were significantly associated with the social support of the families.

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