

Social Support and Parenting Stress among Parents of Children with Autism Spectrum Disorder in Selangor

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Abstract

Previous researchers had proved that parenting stress in parents of children with autism spectrum disorder (ASD) is significantly higher as compared to parents of children with typically developing (TD), and in other developmental disabilities. Therefore, this study aimed to determine the relationship between social support and parenting stress among parents of children with autism spectrum disorder in Selangor. A total of 75 respondents participated in this study which has been identified through a purposive sampling technique from four autism centers in Selangor. The data for this study was collected by using a self-administered questionnaire. Multidimensional Scale of Perceived Social Support (Zimet et al., 1988) and Autism Parenting Stress Index (Silva & Schalock, 2012) were used to determine the relationship between social support and parenting stress. The findings revealed that social support has a negative correlation with parenting stress. It is proven that higher social support is important to reduce stress for parents of children with ASD. Thus, more efforts should be made to support this community.

Keywords: Parents, Children, Social Support, Parenting Stress, Autism Spectrum Disorder

Introduction

Past research showed that stress is an inevitable issue, among parents of children with disabilities. However, researchers had proved that parenting stress in parents of children with autism spectrum disorder (ASD) are significantly higher (Hayes & Watson, 2013; Estes et al., 2013; Altieri & Von, 2009) as compared to parents of children with typically developing (TD), and in other developmental disabilities. According to Rea-Amaya et al (2017), caring for children with disabilities requires high tolerance and patience, as it could take taxes on parents emotionally, physically, and financially. There are many contributing factors to parenting stress in parents of children with ASD (Sharif & Jamil, 2019; Ludlow et al., 2012),

and among the stressor such as family characteristics (age, marital status, family income, level of education), working environment (Laili et al., 2021) and level of social support they received.

Previous research shows that family characteristics do influence parenting stress (Wahab et al., 2022; Manan et al., 2018) and parents tend to practice avoidance as a means of coping with their parenting stress but not for a long period. According to Dardas and Ahmad (2013), parents realize that they need to accept their children's disabilities to cope with their parenting stress. Previous study also proved that parents' levels of distress and depression decreased significantly after the parents accepted their child's disability and embraced their responsibility (Falk et al., 2014). Therefore, social support is one of the factors that have been lightening parental stress and increasing the response to the child's needs (Hassal et al., 2005; Shiba et al., 2016). Social support refers to perceived or instrumental and/or expressive provisions, supplied by the community, social networks, and confiding partners (Lai et al., 2015). Many social supports are available for the parents of children with autism spectrum disorder.

Autism Spectrum Disorder (ASD) was originally an uncommon and unknown disorder for the community, especially in Malaysia as the numbers of those who have ASD used to be relatively small, compared to other diseases such as obesity, heart disease and diabetes. However, ASD has gathered quite an attention among society as the statistics keep increasing day by day and society has significantly become aware of this problem. According to the statistics, there are 300,000 individuals living with ASD in Malaysia (The New Straits Time, 2018). Meanwhile, statistics provided by the National Autism Society of Malaysia (NASOM, n.d) indicated that one in 150 children born worldwide has symptoms of autism. The number of diagnoses of ASD in Malaysia has risen steadily over the past decade, according to Ministry of Health (MOH) data. A smaller scale study showed that autism children in Malaysia is between the ages of 18 to 26 months showed a rate of 1.6 in 1000 children, or approximately one in 625 individuals (Ministry of Health, 2014). Although the exact numbers of children with ASD in Malaysia are unknown, a study conducted by the Ministry of Health Malaysia has stated that 1.6 in 1000 children aged between 18 months to 26 months are diagnosed with ASD. That number is equivalent to 1 per 625 children in Malaysia diagnosed with ASD (Lim, 2015).

Previous studies have found positive correlations between the acceptance level and social support towards parenting stress among parents of children with ASD (Rivard et al., 2014) but this statement was still questionable in the local context. It is presumed that a lack of social support concerning parents of children with ASD led to higher parenting stress. Given the limited ASD research in South-East Asia and in particular Malaysia, researchers have noted that there is a tremendous need for more investigations (Wahab et al., 2022; Laili et al., 2021; Ilias et al., 2017). Therefore, the main objective of this study is to determine the relationships between social support with parenting stress among parents of children with ASD. Explicitly, this paper will also describe family characteristics, social support, and parenting stress. It is anticipated that this study is crucial in helping future potential caretakers of autistic children to deal with their stress levels; and advocate for them to be more knowledgeable in seeking social support from others. Lastly, this research is important due to the research gap in the relationship between the selected variables.

Literature Review

Social Support

In general, social support could be categorized into two areas which are formal and informal social support. Formal social support refers to the social support that is gained from formal settings such as parents' workplace, or even from health professionals or social service support (Cohen, 2004). On the other hand, informal social support includes support from family, friends, and informal groups (Shiba et al., 2016). According to Dunst et al (1986), social support is viewed as the establishment of physical, emotional, informational, and instrumental assistance that is considered helpful and part of one's social network. Shiba et al (2016) have conducted a study in Japan that specifically investigates the relationship between the number of available social support sources and the caregiver burden. Among the examples of informal social support were family members and friends; whilst the examples of formal social support were physicians and visiting nurses. The result of this study indicated that formal social support does not lower the caregiver burden, but informal social support does significantly reduce the caregiver burden. Hence, this study proves that family and friends played a larger role in reducing the caregiver burden compared to outsiders.

Furthermore, a study on the (ab)sence of a concept of social support in parenting research: a social work perspective was conducted by Geens and Vandebroek (2014) in Belgium. Their research focused on reviewing and discussing past articles on how social support can be conceptualized. A total of 225 articles were reviewed and all those articles were selected between the dates of January 2000 and November 2011. The outcome of this study showed that half of the most cited articles had been focusing on the impact social support gave on the psychological functioning of parents and the mother's physical health. In addition, a study by Ekas et al (2010) on the optimism, social support, and well-being of mothers of children with autism spectrum disorder, had mentioned that social support was found as the mediator and moderator of mother's well-being in this study. The results indicated that social support is positively correlated to the mothers' well-being and this result proved that social support does play an important role in increasing the well-being of mothers with ASD children.

Parenting Stress

Parenting stress refers to the stress specific to complex constructs involving behavioral, cognitive, and affective components relating to a person's appraisal of his or her role as a parent (Davis & Carter, 2008; Estes et al., 2013). It is proven that parenting stress in parents with autism spectrum disorder children is significantly higher than parenting stress in parents with typically developing children or parents with developmental disability children (Falk et al., 2014; Firth & Dryer, 2013). This statement was supported by many past studies such as Estes et al (2009) whereby they mentioned that mothers tend to experience greater parenting stress as compared to fathers. This could be explained as mothers are usually the one who deal with the autistic child while fathers are working. The maternal stress in Estes's study was measured in two ways: how it relates to parenting stress and the second one is maternal stress as psychological distress. The Questionnaire on Resources and Stress was used to measure parenting stress. The questionnaire was a self-report questionnaire that consisted of 78 items that measure stress and burden of care in families of children with disabilities. In addition, a study conducted by Phetrasuwan and Miles (2009) on parenting stress in mothers with ASD children discussed the sources of parenting stress as well as examined the relationship between parenting stress and maternal psychological status. They mentioned that it is very stressful when parenting a child with ASD as the disability has a wide range of

symptoms and differences. Among the sources of parenting stress mentioned were the difficulties in interacting with the child, handling their aggressive behaviors, extra caregiving needs and the constant need to advocate on the child's behalf. This statement was supported by other studies (Miranda et al., 2015; McStay et al., 2014)

Social Supports and Parenting Stress

One of the ways of coping strategies adopted by parents to deal with their parenting stress is by seeking social support. Social support is reported to have a linear relationship with parenting stress in parents with autism spectrum disorder children and this is supported by Stuart and McGrew (2009) who stated that parents who have support from their surroundings tend to show a significantly lower level of parenting stress compared to those who did not receive any support. Social support also has been identified as a critical factor that reduces the negative psychological effects of raising a child with ASD as well as other disabilities (Hassall et al., 2005). A study conducted by Laasgard et al (2010) examined loneliness and social support among 39 adolescents' boys with autism spectrum disorder. UCLA Loneliness Scale and Support Scale for Children were used to measure the variables. The result of the study showed a negative correlation between perceived social support and loneliness, where adolescents with autism spectrum disorder show a high rate of loneliness and hence proving the importance of having social support as the protective factor.

Meanwhile, another study by Ekas et al (2010) has explored the role of optimism, social support, and well-being in mothers of children with autism spectrum disorder. One of the goals of this study was to examine the relationships between informal social support and maternal well-being as well as that between optimism and maternal well-being. The result of this study showed that informal support, such as that provided by friends and family, is shown to be effective in reducing stress among mothers of children with ASD. For example, mothers of children with autism spectrum disorder who perceive receiving higher levels of support, especially from spouses and relatives, reported lower levels of depression-related somatic symptoms and fewer marital problems. In addition, a study by Weiss et al (2013) has examined family hardiness, parents' self-efficacy and perceived social support as predictors of family distress among 128 mothers of children with an autism spectrum disorder. The instrument used in assessing perceived social support in this study was the Family Support Scale by (Dunst et al., 1984). The result of this study revealed that family hardiness was negatively related to family distress but was positively related to self-efficacy and perceived social support. Hence this article also proved that social support could serve to increase a family's level of perceived resilience towards parenting stress in parents with autism spectrum disorder.

On the other hand, Dabrowska and Pisula (2010) mentioned that parenting stress may affect their adjustment to take care of their child and the way parents cope with the stress indicates a successful adaptation of the parents. They further added that there are three basic types of resources that a family may use to manage a crisis, which are personal resources of family members, internal resources of the family system and social support from resources external to the family. Dabrowska and Pisula also mentioned that parents with a lower level of stress usually are those who seek informal support from their family members or their peers. Furthermore, research on factors predicting stress, anxiety, and depression in parents of children with autism spectrum disorder also mentioned that social support was considered one of the factors that contributed to parenting stress. Moreover, Smith et al (2012)

conducted a study on the impact of social support on the psychological well-being of 406 mothers of children with autism spectrum disorder child. The findings showed that higher levels of social support are associated with a negative impact on psychological distress, negative mood, and depressive symptoms. Dardas and Ahmad (2015) also stated that parents might need support services that could help them to develop positive acceptance and to adapt to their responsibilities towards their autistic child.

Additionally, a qualitative study was conducted in Malaysia by Ilias et al (2017) interviewed eight Malaysian mothers who have autistic children. The informant comprised four Chinese, three Malay, and one Indian mother. It is interesting to note that social support was found to be a successful coping strategy for mothers of children with autism spectrum disorder. However, all mothers find difficulty dealing with society, especially in the formal setting as they do not get support from their workplace or the schools of their children. The mothers also claimed to feel lonely raising their children due to the lack of social support and the result of reducing their social activity. Besides, Ilias et al. stated that five of eight mothers claimed that family conflict regularly happened, and it had given a tremendous burden on the mothers. Nonetheless, although autism is still an unknown issue in Malaysia, six out of the eight mothers described receiving various community support, mostly from ASD parent support networks or religious institutions.

Finally, another study on parenting stress among Malaysian parents of children with ASD was conducted in Malaysia by (Lee at.al., 2017). The respondents for this study are 30 parents of children with ASD and 36 parents with typically developing children. All of them are given a set of Parenting Stress Index questionnaires (Abidin, 1995). The result revealed that parents of children with ASD have significantly higher scores of parental distresses compared to parents with typically developing children. This result could be due to the lack of social support in the community and knowledge regarding autism. To sum up, many foreign countries have discussed the relationship between social support with and parenting stress in parents of children with ASD, but there is still limited research in Malaysia. Nevertheless, all this research pointed out the same outcome which is social support does have an influence on parenting stress where it lessens the parenting stress in parents with autism spectrum disorder children.

Methodology and Research Design

This study employed correlational research with quantitative survey methodology to gather information regarding the relationship between social support and parenting stress. This study was conducted in Selangor which was further specified into four (4) organizations related to ASD

- (i) Ideas Autism Centre (IAC) in Rawang.
- (ii) The Autism Cafe Project in Puchong
- (iii) The National Autism Society of Malaysia (NASOM) Klang.
- (iv) The National Autism Society of Malaysia (NASOM) Gombak.

The target populations for this study are the parents of children with ASD and residing in Selangor only. Permission for field data collection was obtained from the identified center. The NASOM headquarters has given permission to gather data in NASOM settings. The researcher explained the study protocol to the administrator and parents. Before data collection, written consent was obtained from the respondents. The participants were

informed that their consent was voluntary, that they had the option to refuse to participate, and that their anonymity and confidentiality would be protected. Due to some limitations, only 75 parents participated in this study.

Variables and Measurement

Social Support

The Multidimensional Scale of Perceived Social Support (MSPSS) by Zimet et al (1988) was used to measure respondents' perceptions of social support from three specific sources: family, friends, and significant others. The instrument consists of a 12-item scale that uses a 7-point Likert-style response format: (1 = Very Strongly Disagree, 2 = Strongly Disagree, 3 = Mildly Disagree, 4 = Neutral, 5 = Mildly Agree, 6 = Strongly Agree, and 7 = Very Strongly Agree) to increase response variability and minimize a ceiling effect (Zimet et al., 1988). All the items in the questionnaire were later summed to obtain a total score. The three subscales in this questionnaire: Family, Friends, and Significant Other, were each assessed with four items. The examples from the family subscale are, "I get the emotional help and support I need from my family" and "My family really tries to help me". In addition, the examples from the friend's subscale are: "My friends really try to help me" and "I can count on my friends when things go wrong". Lastly, the examples from the significant other subscale are, "There is a special person in my life who cares about my feelings" and "There is a special person who is around when I am in need". Higher scores indicated higher perceptions of social support while lower scores indicated lower perceptions of social support.

Parenting Stress

The parenting stress in this study was measured using the Autism Parenting Scale Index (APSI). APSI is an instrument developed by Silva and Schalock (2012) consisting of 13 items that were used to measure parenting stress specific to the core and co-morbid symptoms of autism. To be more precise, it was designed to indicate how much stress parents were experiencing and what factors were contributing to this stress. The items in this questionnaire fall into three categories: core social disability, difficult-to-manage behavior, and physical issues. This questionnaire uses the Likert-type scale with seven points, where 1 = Not Stressful, 2 = Sometimes Stressful, 3 = Often Create Stress, 4 = Very Stressful daily, and 5 = So Stressful We Feel We Cannot Cope.

Both MSPSS and APSI instruments have a coefficient above 0.9 which is considered a high coefficient. The Cronbach's alpha coefficient for MSPSS in the pilot study was 0.962 while in the actual study was 0.957. On the other hand, the coefficient for the APSI instrument during the pilot study was 0.923 while in the actual study, it was 0.912. Since both instruments have high coefficients, they are considered reliable instruments for this study.

Data Analysis

In evaluating the data, Statistical Package for the Social Science for Windows (SPSS) version 21 was used to analyze the data. In this study, reliability analysis, univariate analysis and bivariate analysis were done. Reliability analysis was conducted to assess the reliability of the instruments of the Multidimensional Scale of Perceived Social Scale and Autism Parenting Stress Index. A univariate analysis was generated using SPSS in this study to describe the information about the respondent's family characteristics and social support. These descriptive analyses were reported using mean, standard deviation, minimum and maximum.

Pearson correlation was used to determine the relationship between social support and parenting stress.

Results and Discussion

Descriptive Analysis

Table 1 shows the demographic characteristics of 75 respondents who were involved in this study. More than half of the respondents (56.76%) were aged between 31 years old until 40 years old. About 32.42% of the respondents, aged from 41 to 50 years old. Data also revealed that the youngest respondent was 23 years old, while the oldest was 74 years old with the mean age was 39 years old.

On the other hand, although 21 data are missing on the spouse’s age, the mean age for the respondent’s spouse recorded was also 39 years old. The majority age group of the spouses recorded was between 31 and 40 years old with a total of 40.0% (n=30), followed by the age group of between 41 and 50 years old with 20.0% (n=15). The youngest spouse’s age recorded was 23 years old while the oldest spouse was 70 years old.

Based on the data analyzed, the mean age for the child was 7 years old and 8 months while most of the children’s age in this study were between 6 to 10 years old with 45.32% (n=34) of the total respondents. The second highest age group was between 1 and 5 years old with 34.67% (n=26) of the total respondents while the lowest age group was between 16 to 25 years old with a total of 5.34% (n=4) respondents only.

Table 1
Descriptive of Family Characteristics

Variable	n (%)	Mean	S.d.
Parent’s Age		39.37	7.25
21-30	5 (6.67)		
31-40	43 (57.33)		
41-50	24 (32.0)		
51-60	2 (2.67)		
61-70	0		
71-80	1 (1.33)		
Parent’s Total Years of Formal Education		14.87	2.468
9	1 (1.33)		
11	13 (17.33)		
13	2 (2.67)		
14	18 (24.0)		
16	30 (40.0)		
17	2 (2.67)		
19	9 (12.0)		
Parent’s Income		4843.92	5487.87
RM 0 - RM 2, 500	20 (26.67)		
RM 2,501 – RM 5,000	27 (36.0)		

RM 5, 001 – RM 10,000	12 (16.0)		
> RM 10, 000	3 (4.0)		
Missing	13 (17.33)		
Spouse's Age		39.06	7.80
21-30	6 (8.0)		
31-40	30 (40.0)		
41-50	15 (20.0)		
51-60	2 (2.67)		
61-70	0		
71-80	1 (1.33)		
Child's Age			
1-5	26 (34.67)		
6-10	34 (45.32)		
11-15	11 (14.67)		
16-20	2 (2.67)		
21-25	2 (2.67)		

*missing (respondents did not fill in)

Parent's Total Years of Formal Education

The parent's total years of formal education were calculated based on their education levels. Eight options were given in the questionnaire which were: Did not attend primary school, SRP/PMR, SPM, STPM, Diploma, Degree, and Master/PhD. Based on this, their total years of formal education were obtained. In this study, the mean years of formal education were 15 years with most of the respondents (40.0%, n=30) are parents with 16 years of formal education, followed by parents with a total of 14 years of formal education (24.0%, n=18). The respondents had a minimum of 9 years of formal education and a maximum of 19 years of the total formal year of education.

Parent's Income

The mean income of the respondents in this study was RM 4844 (SD = 5488), where 62 out of 75 respondents filled up the income section. From the data, the respondents' incomes were divided into four categories as shown in the table above. Most respondents (36.0%, n=27) have an income between RM 2501 and RM 5000, followed by having an income of RM 2500 and below (26.67%, n=20). The data also showed that the minimum income recorded from the respondents was RM 600 while the highest income recorded was RM 40,000 a month.

Descriptive Analysis of Social Support

Social support is one of the contributing factors that can diminish parenting stress, especially within a family with a disabled child. Stuart and McGrew (2009) stated that parents who have support from their surroundings tend to show a significantly lower level of parenting stress as compared to those who did not receive any support. Based on the current finding, social support can be divided into three levels, low, moderate, and high. As seen in Table 2, 54.67% (n=41) of the parents perceived a high level of social support from their family and friends while 33.33% (n=25) of them reported having a moderate level of social support. Parents who have low social support in this study were only 8.0% (n=6) from the total of 75 respondents

and 3 data on social support were missing in this study. Meanwhile, the Cronbach's α values of the three subscales of family, friends, and other important members were 0.91, 0.91, and 0.87, respectively, and the total scale reliability was 0.95. Table 2- shows the level of social support obtained from the data.

Table 2

Level of Social Support

Criteria	n (%)
Social Support	
Low Support	6 (8.0)
Moderate Support	25 (33.33)
High Support	41 (54.67)
Missing	3 (4.0)

Social Support and Parenting Stress

The relationship between social support and parenting stress among parents of children with autism spectrum disorder was analyzed in this study by using Pearson's correlation. The result in **Table 3** showed a negative correlation between the two variables ($r = -0.265$, $p = 0.021$). Although the strength of the correlation is low, there is still a significant relationship between social support and parenting stress. A negative correlation means that the higher the social support, the lower the parenting stress and vice versa. This result was supported by Ekas et al (2010) who stated that mothers with ASD children who perceive receiving higher levels of social support were reported to have lower levels of depression-related symptoms. This is consistent with the result of this study where the majority (54.67%, $n=41$) of the respondents were found to have a high level of social support from their family and friends. Weiss et al. (2013) also stated that social support can increase a family's level of perceived resilience toward parenting stress in parents with an autism spectrum disorder. Hence, it is proven that high social support correlates with low levels of parenting stress.

Table 3

Social Support and Parenting Stress

Variables	Parenting Stress	
	r	p
Social Support	- 0.265*	0.021

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

Discussion

Researchers have begun to investigate the impact of social support on well-being among parents of children with disabilities, including autism. This study aimed to determine the relationship between social support with parenting stress among parents of children with an autism spectrum disorder in Selangor. The instrument used was the Multidimensional Scale of Perceived Social Support (MSPSS) by Zimet et al (1988) which consisted of 12 items and the Cronbach's alpha recorded in the actual study was 0.957. The levels of social support perceived by the parents were categorized into three levels which were low, moderate, and high social support. Based on the data obtained, most of the parents showed that they have

high social support with a total of 54.67% (n = 41) from the total of 75 respondents. Nonetheless, 6 of the respondents perceived low social support (8.0%) from other people.

Pearson correlation was used to test the hypothesis for this objective. The result showed that social support does have a negative significant relationship with parenting stress ($r = -0.265$, $p = 0.021$). This means that the higher the level of social support received by the parents, the lower their parenting stress. This study confirmed that parents' perception of social support is an effective protective factor for their parenting stress (Sharif & Jamil, 2019; Ubeh et.al., 2017). Therefore, siblings, family members, extended relatives, friends, neighbors, employer, and other people in the community must provide constructive support to parents of children with ASD.

Some limitations should be highlighted here, to ensure maximum benefits. First, the researcher only managed to recruit 75 respondents from Selangor only. It does not adequately reflect the parental population of young children with ASD due to a lack of big samples. Therefore, these findings may not be generalizable to all parents with ASD children who are residing in other states in Malaysia. Future research might expand this study by using more diverse samples and different settings to provide greater generalization. Moreover, the current study did not attempt to investigate other variables that may influence parenting stress. Hence future studies should explore the influence of other factors.

Regardless of these limitations, this study contributes to the available body of knowledge by enhancing the current understanding of the relationship between social support and parenting stress among parents of children with ASD. This study has also provided value added to the Ecological System Theory (Bronfenbrenner, 1995). The findings of this study can contribute to the existing data on parenting stress in parents with ASD children Selangor. Besides, this study also proved that parenting stress issues in parents with ASD children in Malaysia should be addressed by the authorities in the future. Findings from this study also provide information on the importance of social support to parents with ASD children. There were many other characteristics that could affect parenting stress as shown by past research that were not investigated in this study. Thus, future research should further include other potential contributing factors to parenting stress such as the child's age group and the autism severity level.

To sum up, the findings offer crucial information that potentially can be used to empower parents with knowledge and skills in assisting their disabled children. It is proven that higher social support is important to reduce stress for parents of children with ASD. Thus, more efforts should be made to support this community.

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