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Social Support and Stress among Parents with Autism Spectrum Disorder

Rosilah Wahab¹, Syamsul Anwar Sultan Ibrahim¹, Kamilia Asyiqin Mohd Fahmy¹, Winnie Philip²

¹ Faculty of Health Sciences, Universiti Teknologi MARA, Selangor Campus, 42300 Bandar Puncak Alam, Selangor.

² College of Applied Medical Sciences, King Saud bin Abdulaziz University for Health Sciences, Riyadh, Saudi Arabia.

rosil806@uitm.edu.my, kamiliaasyiqin2308@gmail.com, syamsul2893@uitm.edu.my, philipw@ksau-hs.edu.sa
Tel: +6012-6717576

Abstract

Common social interaction challenges, also patterns of restricted and repetitive behavior, characterize Autism Spectrum Disorder (ASD). This study aimed to determine the relationship between the ASD child's parents' social support and parental stress. Samples of parents were collected through the National Autism Society of Malaysia. A demographic questionnaire, parents' stress level was measured using the Parental Stress Scale (PSS) and perceived social support was measured using Multidimensional Scale of Perceived Social Support (MSPSS). Findings revealed that ASD child's parents were experiencing high social support, results showed a significant negative relationship between perceived social support and parental stress ($p < 0$).

Keywords: Autism Spectrum Disorder (ASD), Parental Stress, social support

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1.0 Introduction

At every stage of developmental life, responsibilities always tend to increase as well as stress and anxiety that can lead to various adverse effects or positive benefits on the individual's ability to cope. All parents face regular parenting-related hassles, including those of well-behaved, happy children. Yet parenting stress can be attributed to clinically significant adolescent parents with mental, emotional, and behavioral problems.

Autism Spectrum Disorder (ASD) is defined by the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM) barriers in social interaction and patterns of restrictive and repetitive behaviors. Meanwhile, Xin Lee (2017) described ASD as a neurodevelopmental childhood disorder related to cognitive and language impairments. Statistics published by the National Association of Autism Malaysia (NASOM) in 2013, as quoted from the Utusan Malaysia newspaper, indicated that one among the 150 children born worldwide has symptoms of autism. Of that number, an estimated 47,000 children, age ranging from six months to their late 20s in Malaysia suffer from it (Zakaria, 2018). As cited in Mohd Salleh et al. (2018), a smaller-scale study found that autism in Malaysia among children between the ages of 18 and 26 months showed a prevalence of 1.6 in 1000 children or around 1 in 625 people.

2.0 Literature Review

The burden of caring for a disabled child will increase the stress levels of parents, which lead them to search for, create, and use strategies to deal with these stresses. As a result, having a robust social network allows parents to share responsibilities and worries with others to get emotional support and stress management from people they know like friends, family and neighbours (Rehab & Mona, 2019). Social

support may also help reduce the burden of raising a kid with ASD by providing emotional and practical assistance is frequently absent in formal services (Pepperell et al., 2018). Informal support from friends and family, in particular, is beneficial in reducing stress for parents of children with ASD. Drogomyretska et al. (2020) indicate that receiving social support from friends can significantly reduce the stress levels experienced by parents raising a child with ASD. Meanwhile, Cuzzocrea et al. (2016) found that spousal support and marital satisfaction are associated with lower stress levels in parents of children with intellectual disabilities. Thus, understanding a family is fundamental to alleviate stress not just for parents but also for children themselves. Parents can perceive emotional support and adaptation for stress management with a strong social network in which they can discuss their concerns and issues with those around them (Rehab & Mona, 2019). The impact of stress on mothers and fathers has been well researched. According to Storms (2012), mothers reported more daily stress than fathers. When it came to raising a child with ASD, he also thought that essential to figure out if fathers experience increased stress. The authors also discussed that although fathers were included, for young children with ASD, mothers' stress and her adaptation techniques could not be directly comparable to fathers' stress and his adaptation. He also discovered that there was a significant difference in stress levels between mothers and fathers. Due to the small sample size in their study, the author thought that disparities in stress levels between mothers and fathers rearing their young ASD children might be higher in a larger sample. Stress level among parents with ASD children as well as to determine the relationship between demographic data with perceived social support and parental stress among parents with ASD children. This study looked at the relationship between perceived social support and parental stress among parents with ASD children. For this study, three hypotheses were proposed. The first, hypothesis, there is a significant relationship between demographic data with perceived of social support among parents with ASD children. Second hypothesis, there is a significant relationship between demographic data with parental stress among parents with ASD children. For third hypothesis, there is a significant relationship between perceive social support and parental stress among parents with ASD children

3.0 Material and Methods

3.1.1 Design

A cross-sectional survey was conducted to 116 parents with ASD children from January to April 2021. This design was chosen because it is easy to use, and it helps researchers simultaneously compare several different variables and determine the prevalence of situation or problem by taking the cross-sectional area of the population (Kumar, 2013). This study was conducted through an online questionnaire survey via Google Form was distributed using a link toward parents who have autistic children in the National Autism Society of Malaysia (NASOM) in Selangor and Kuala Lumpur. This study has received ethical approval from the Universiti Teknologi MARA (UiTM) Ethic Committee. The NASOM headquarters has given permission to gather data in NASOM settings. The participants' confidentiality and anonymity were protected, as was the privacy of their data.

3.2 Data collection procedure

A demographic questionnaire, Multidimensional Scale of Perceived Social Support (MSPSS) and Parental Stress . Scale (PSS) were used to obtain data. The level of stress of parents with ASD children was measured using the Parental Stress Scale (PSS), and perceived social support was measured by using the Multidimensional Scale of Perceived Social Support (MSPSS). The Multidimensional Scale of Perceived Social Support (MSPSS) was used as a questionnaire to assess perceived social support. The Parental Stress Scale (PSS) attempts to measure the levels of stress a parent experiences (Berry & Jones, 1995) moreover from the perspective of "individual differences in the level of stress related to raising children" and focuses on the individual's perception of parental stress (Nielsen et al., 2022)

4.0 Results

4.1 Description of participants

A total of N=116 participants from the parents of autistic children who enrolled in NASOM in Selangor and Kuala Lumpur Table 1 presents descriptive statistics on the demographic characteristics of the participants. The ASD child items included the child's current age. Of the 116 parents of ASD children, 85.3% (n=) were mothers, and 14.7% (n=) were fathers. Most of the participants (95.7%) were married, aged between 31-40 years old (64.7%), 81.9% of them went to college or University, and the majority of them have four years old of ASD children (37.9%)

Table 1: Descriptive statistic of participants' demographic characteristics

Characteristics	Group	n (%)
Parents' role	Mother	99 (85.3)
	Father	17 (14.7)
Marital status	Married	111 (95.7)
	Divorced	5 (4.3)
Parents' age	20-30 years	24 (20.7)
	31-40 years	75 (64.7)

	> 41 years	17 (14.7)
Educational status	Primary	18 (15.5)
	High school	3 (2.6)
	College/university	95 (81.9)
ASD Childs' age	4 years	44 (37.9)
	5 years	36 (31.0)
	6 years	36 (31.0)

4.2 Parental Stress among Parents with ASD Children

Table 3 demonstrates the mean (SD) of parents with ASD children regarding each item of the Parental Stress Scale (PSS). Higher scores in these scales signify high parental stress. The mean (SD) of total score stress of parents was 44.16 (8.88). This result demonstrates that samples from parents of autistic children experienced high parental stress. The lowest item score was the mean score for item 7 (mean = 1.22, SD = 0.43), followed by item 6 (mean = 1.29, SD = 0.54), item 5 (mean = 1.32, SD = 0.55), item 18 (mean = 1.54, SD = 0.75), item 1 (mean = 1.57, SD = 0.77) and item 2 (mean = 1.73, SD = 1.16). Item 7, 6, 5, 18, 1, 2 was positive questions. Therefore, scores for the positive questions need to be reversed. It can be shown that the mean average among parents with ASD children answers "strongly disagree" to express feelings and perceptions about the parenting experience. The highest item score was the mean score for item 4 (mean = 4.76, SD = 0.45). This can be seen in the fact that majority of parents gave approximately a five rating (strongly agree), indicating that they are extremely concerned about whether or not they are doing enough for their autistic children. Aside from that, item 3 also showed the second highest mean score (mean = 4.59, standard deviation = 0.73), for which parents also gave approximately of strongly agree that caring for a child with autism, sometimes requires them more time and energy they must put into it

Table 3: Scores of Parental Stress Scale among parents with ASD children according to scales (n=116)

Scale	Mean (SD)
Item 1	1.57
I am happy in my role as a parent*	(0.77)
Item 2	1.73
There is little or nothing I wouldn't do for my child(ren) if it were necessary*	(1.16)
Item 3	4.59
Caring for my child(ren) sometimes takes more time and energy than I have to give	(0.73)
Item 4	4.76
I sometimes worry whether I am doing enough for my child(ren)	(0.45)
Item 5	1.32
I feel close to my child(ren)*	(0.55)
Item 6	1.29
I enjoy spending time with my child(ren)*	(0.54)
Item 7	1.22
My child(ren) is an important source of affection for me*	(0.43)
Item 8	1.45
Having child(ren) gives me a more certain and optimistic view for the future*	(0.76)
Item 9	2.79
The major source of stress in my life is my child(ren)	(1.21)
Item 10	3.51
Having child(ren) leaves little time and flexibility in my life	(1.09)
Item 11	2.45
Having child(ren) has been a financial burden	(1.20)
Item 12	3.05
It is difficult to balance different responsibilities because of my child(ren)	(1.17)
Item 13	2.54
The behavior of my child(ren) is often embarrassing or stressful to me	(1.21)
Item 14	2.03
If I had it to do over again, I might decide not to have child(ren)	(1.22)
Item 15	3.25
I feel overwhelmed by the responsibility of being a parent	(1.34)
Item 16	3.03
Having child(ren) has meant having too few choices and too little control over my life	(1.20)
Item 17	2.03
I am satisfied as a parent*	(0.82)
Item 18	1.54
I find my child(ren) enjoyable*	(0.75)
Total score stress	44.16
	(8.88)

*reverse-scored

4.3 Relationship between Demographic Data with Perceived Social Support and Parental Stress among Parents with ASD Children

The present study looked at the relationship between the characteristics of parents and total perceived of social support. As shown in Table 4, the present study found only one statistically significant result. Independent samples t-test, which examined the relationship between marital status with total perceived social support, indicated mean stress level parents of autistic children that are still married experienced a higher level of perceived social(15.37)]. These results suggest that marital status, which is divorced, really does have an effect on perceived social support. Therefore, according to the present study, the null hypothesis was rejected since p-value < 0.05, and 95% cross 0. Second, the ANOVA test examined the relationship between parents' age, educational status and ASD child age with total perceived social support. Results demonstrated that there is no significant relationship with the null hypothesis was accepted since p-value > 0.05, and 95% CI cross 0; thus, there is no significant relationship between age and educational status with parents perceived of social support among parents with ASD

Table 4: Relationship between demographic data and perceived of social support among parents with ASD children

Demographic	Group	Total social support mean (SD)	p value
Parents' role	Mother	63.44 (14.57)	0.16
	Father	68.65 (9.50)	
Marital status	Married	64.82 (13.73)	0.03*
	Divorced	50.60 (15.37)	
Parents' age	20-30 years	64.25 (12.17)	0.81
	31-40 years	64.65 (14.40)	
	> 41 years	62.18 (15.40)	
Educational status	Primary	65.11 (14.53)	0.20
	High school	50.00 (13.08)	
	College/university	64.48 (13.87)	
ASD Childs' age	4 years	65.11 (10.18)	0.09
	5 years	67.14 (14.41)	
	6 years	60.17(16.88)	

*Statistically significant at p<0.05

4.4 Relationship between demographic data with total parental stress levels among parents with ASD children

Identification from the present study examined the relationship between parents' characteristics and total parental stress levels. First, independent samples t-test that examined the relationship between parents' role and marital status with total parental stress levels indicated that no significant difference between mother and father stress which both exhibit high levels of stress. Meanwhile, it can be seen that divorced parents produced more stress than parents that is still together [(M = 46.20, SD = 1.48 vs M = 44.06, SD = 9.06)]. Still, the result is not statistically significant, meaning there is no relationship between parents' role and marital status with total parental stress levels. Second, the ANOVA test examined the relationship between parents' age, educational status and ASD child's age with total parental stress levels. Results also demonstrated that parents' age, educational status as well as ASD child's age have no significant relationship with parents' stress level. The null hypothesis was not rejected since p-value > 0.05, and 95% CI cross 0; thus, there is no significant relationship between demographic variables and parental stress level among parents with ASD children. The present study identified no statistically significant findings, as indicated in Table 5.

Table 5: Relationship between demographic data with total parental stress levels among parents with ASD children

Demographic	Group	Total parental stress mean (SD)	p value
Parents' role	Mother	44.15 (9.19)	0.99
	Father	44.18 (7.03)	
Marital status	Married	44.06 (9.06)	0.06
	Divorced	46.20 (1.48)	
Parents' age	20-30 years	45.88 (8.02)	0.45
	31-40 years	43.40 (9.34)	
	> 41 years	45.06 (7.91)	
Educational status	Primary	43.83 (6.79)	0.94
	High school	42.67 (8.39)	
	College/university	44.26 (9.30)	
ASD Childs' age	4 years	45.36 (8.82)	0.52
	5 years	43.53 (8.48)	

6 years

43.31 (9.40)

4.5 Relationship between Perceived Social Support and Parental Stress among Parents with ASD Children

Pearson correlations were computed between the perceived of social support and parental stress among parents with ASD children. The results were statistically significant, weak negative correlation between the two variables ($r = -.217$, $n = 116$, $p\text{-value} = 0.02$) as shown in Table 6. The null hypothesis was rejected since $p\text{-value} < 0.05$, and 95% CI cross 0; thus, there is a significant negative relationship between perceived social support and parental stress among parents with ASD children

Table 6: Correlation between perceived social support and parental stress among parents with ASD children ($n=116$)

Variables	M	SD	1.	2.
1. Parental stress	44.16	8.876	-	-.217*
2. Perceived social support	64.21	14.03	-.217*	-

*Statically significant at $p < 0.05$

5.0 Discussion

This study shows in general that the parents of children with autism spectrum disorder (ASD) have been affected by their special needs children. It was supported by the data analysis in this study since it showed that parents had higher results in the stress score, which is consistent with findings from Wang (2016) in the United States and China samples. Meanwhile, the present study found that most parents have an average total stress score of 44.16. Although a large percentage of parents experienced high levels of stress, the present study found the average score can be considered as high parental stress even though it does not exceed half of the total score, which is 90. Since the instrument used to have no cut-off or specific interpretation for the results, the average score can be considered as high parental stress. In addition, samples from parents also showed more variation in their stress scores. These could be due to the fact that the nature of ASD children itself puts extra caregiving responsibilities on parents, resulting in increased parental stress owing to cognitive and social deficits, children need to be more reliance on parents, at the same time, parents also worry about their children's unpredictable future. The stress experienced by parents adversely influences their ability to take care of their children, and their mental and physical well-being will also be affected (Wang, 2016). Studies using an instrument other than PSS also have produced similar results, with Xin Lee (2017), parents of children with ASD were found to have the highest stress levels. The only marital status is shown to be statistically significant ($p < 0.03$) means that marital status does have an effect on parents' perceived social support, and their relationship is significant. Social support may be a very useful resource for families during various periods of life. Notably, many parents remain primary caregivers for their children and throughout adulthood. Freedman et al. (2012) discussed that the spouse relationship might be the sole support system for some families because many families feel isolated from outside social support. Regarding the correlation that has been run, the result showed a negative relationship between perceived social support and stress levels ($p < 0.05$). Thus, it indicated a significant relationship between parents' perceived social support and parental stress, although in a negative relationship which means that higher levels of social support are correlated with lower levels of parental stress. This research finding was supported by a finding from Drogomyretska et al. (2020), which indicates that perceived social support can significantly influence levels of parental stress usually associated with raising a child with ASD. Parents who believe they have social support may experience less stress, positive parental behavior is more favorable than parents who feel they have no social support (Respler-Herman et al., 2012). As a result, social support may help alleviate the negative impacts of parental stress on parenting behaviors. Consistent with Smith et al. (2012), higher levels of social support have been linked to reduced levels of a negative impact and psychological distress in studies of parents of children with ASD. , present study also found that all demographic *characteristics* does not affect the overall stress level felt by these parents As a result, in addition to the rigorous characteristics of ASD, some parents may not have more resources to cope with these needs, which increases the risk of their family disruption, including marital breakdown. At the same time, their stress will continue to increase. Hence, social support appears to both avoid and relieve stressful circumstances. It lacks can lead to abandonment, despair and anger, which can have negatively influenced the family's experience with disability (Lima et al., 2016)

6.0 Conclusion and Recommendation

Overall, it revealed a significant negative relationship between perceived social support and stress among parents with ASD children. Higher levels of social support are correlated with lower levels of parental stress. Meaning that higher levels of social support are correlated with lower levels of parental stress that indicate perceived social support can significantly influence levels of parental stress usually associated with raising a child with ASD. As a result, it is necessary to support and provide both parents with solutions that they believe will best help them with the challenges of raising children with ASD. It is recommended for a larger sample size from parents of ASD children to get more detailed results. It does not adequately reflect the parental population of young children with ASD due to a lack of big samples. Rather than studying their perceived social support from informal support (partners, family and friends), it may be

necessary to perceive it from formal social support, such as therapists and specialist who deal with families of autistic children, to determine the needs of parents and offers parents of young children with ASD with variety of coping methods. Parents of children with ASD of various ages should be included

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