

Parenting Stress among Malaysian Parents of Children with Autism Spectrum Disorder (ASD)

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ABSTRAK

Kecelaruan spektrum Autisme (ASD) merupakan sejenis ketidakseimbangan perkembangan neuro kanak-kanak yang dikaitkan dengan kecacatan kognitif dan bahasa. Penyelidikan sebelum ini mendapati bahawa kanak-kanak yang mempunyai ketidakseimbangan perkembangan meningkatkan tahap tekanan ibu bapa. Namun, ibu bapa yang mempunyai anak ASD mengalami tahap tekanan yang lebih tinggi berbanding ibu bapa yang mempunyai kanak-kanak ketidakseimbangan perkembangan yang lain. Justeru, kajian ini bertujuan untuk mengkaji perbezaan tahap tekanan antara ibu bapa yang mempunyai kanak-kanak ASD dan ibu bapa yang mempunyai kanak-kanak perkembangan tipikal (TD) yang dikategorikan dalam kumpulan kontrol. Borang indeks tekanan ibu bapa, terbitan ketiga digunakan untuk menilai tahap tekanan dalam kalangan 30 ibu bapa yang mempunyai kanak-kanak ASD dan 36 ibu bapa yang mempunyai kanak-kanak TD. Sampel ibu bapa yang mempunyai kanak-kanak autisme dikumpul dari Pusat Perubatan Universiti Kebangsaan Malaysia (PPUKM), Hospital Tangkak, dan Pusat Autisme (NASOM) di Muar dan Segamat. Ibu bapa yang mempunyai kanak-kanak ASD mempunyai tahap tekanan yang signifikan lebih tinggi berbanding ibu bapa mempunyai kanak-kanak TD ($p < 0.001$). Ibu bapa yang mempunyai kanak-kanak lelaki ASD mempunyai tahap tekanan yang signifikan lebih tinggi berbanding ibu bapa yang mempunyai kanak-kanak lelaki TD ($p < 0.001$). Ibu bapa yang mempunyai kanak-kanak perempuan ASD mempunyai tahap tekanan yang signifikan lebih tinggi berbanding ibu bapa yang mempunyai kanak-kanak perempuan TD ($p < 0.001$). Intervensi terhadap kanak-kanak ASD tidak seharusnya mementingkan pengurangan simptom-simptom utama sahaja tetapi juga harus memberi perhatian terhadap kesihatan mental keluarga.

Kata kunci: autisme (ASD), kanak-kanak, tahap tekanan ibu bapa

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ABSTRACT

Autism Spectrum Disorder (ASD) is a neurodevelopmental childhood disorder associated with cognitive and language impairments. Previous research found that children with developmental disorders increase parenting stress but parents of children with ASD, specifically have recorded higher parenting stress than any other developmental disabilities. Hence, this study investigates the difference in parenting stress levels among parents of children with ASD compared to a typical development (TD) control group. Parenting Stress Index, 3rd Edition Short Form was used to assess the parenting stress levels of 30 parents of children with ASD and 36 parents of TD children. Parents of children with ASD were sampled at Universiti Kebangsaan Malaysia Medical Centre (UKMMC), Tangkak Hospital and National Autism Society of Malaysia (NASOM) in Muar and Segamat. Parents of children with ASD recorded significantly higher levels of parenting stress compared to the TD group ($p < 0.001$). Parents of male children of ASD recorded significantly higher levels of parenting stress compared to the parents of male children of TD group ($p < 0.001$). Parents of female children of ASD also recorded significantly higher levels of parenting stress compared to parents of female children of TD group ($p < 0.001$). Intervention towards ASD children should not only focus on minimizing the core symptoms but should also pay attention to the family's mental health as well.

Keywords: Autism Spectrum Disorder (ASD), children, parenting stress

INTRODUCTION

Parents experience stress when raising children. Nevertheless, bringing up children with disabilities is even more a gargantuan task with physical, psychological and mental effects. Parents often sacrifice their time, energy and financial resources in order to cope with their children's impairments characterised by a wide range of symptoms. However, parents of children with Autism Spectrum Disorder (ASD) consistently reported higher levels of parenting stress compared to the parents of typically developing (TD) children and those with other neurodevelopmental disorders like Down Syndrome (Mancil et al. 2009).

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterised by deficits in communication skills, social interactions and restricted, repetitive and stereotyped patterns of behaviours. This condition is aggravated by the presence of comorbid conditions in which children with ASD are often associated with language disorders, cognitive delays, and anxiety and mood disorders. Brain development in ASD follows an abnormal pattern as shown in Magnetic Resonance Imaging (MRI) scans with accelerated unusual brain growth in early life that causes the enlargement of brain during childhood. Nonetheless, brain volume among adolescents and adults with ASD

atypically decreases slightly in terms of structural volume and neuron number (Courchesne et al. 2010). Behavioural and emotional outbursts, are another core features among individuals with ASD in which there is an association between ASD and alexithymia (Szatmari et al. 2008). In turn, alexithymia is directly related to aggression (Konrath et al. 2012). Parents rated Disruptive Mood Dysregulation Disorder (DMDD) as the most prevalent among children with autism compared to children with Attention Deficit Hyperactivity Disorder (ADHD)-Combined and ADHD-Inattentive (Mayes et al. 2015). The mood swings and temper outbursts could be attributed to the higher levels of cortisol, serotonin and lower levels of oxytocin among individuals with ASD which lead to repetitive behavior (Yang et al. 2015).

There are limited studies that focus on parents of children with ASD or specifically parenting stress among these parents with contradictory results. Not all demographic factors were investigated. In 2007, Schieve, and colleagues compared the relative aggravation range among parents of children with and without ASD (Schieve et al. 2007); in 2013, Hassan and Inam studied the difference in parenting stress levels among fathers and mothers of children with ASD (Hassan & Inam 2013). In 2014, Zamora, and his team determined the difference in parental distress and parent-child dysfunctional interaction among parents of female and male children with ASD. The relationship of other demographic factors like number of siblings, age of children with ASD, gender of parents

and ethnic groups with parenting stress were not clearly identified.

There is a misassumption that children with ASD do not undergo puberty. Indeed, the reality is that all children undergo puberty despite Intelligence Quotient (IQ) and social skills. Children with ASD often experience puberty earlier than other typical peers of the same age. Hormone surges during adolescence lead to emotional outbursts such as unreasonable mood swings, aggression, arguing and defiance. Some may even include increased self-injurious behaviour. Logically, parents of adolescents with ASD should have a higher level of parenting stress compared to parents of children with ASD at infancy. However, this conclusion seems premature due to the relative lack of research on parenting stress among different ages of children with ASD. Identifying critical factors contributing to parenting stress enable the parents to handle ASD in their children better.

Raising children involved identification of ASD and proper handling of the children with this disorder. The current knowledge on ASD has enabled us to identify and embrace children with this disorder. At the same time, we should pay attention to parenting stress among the parents with ASD children. Hence, this study aimed to investigate the difference in parenting stress between parents of children with ASD and parents of TD children. The effects of demographic factors such as age of ASD children and gender of parents of children with ASD on the parenting stress were also investigated.

MATERIALS AND METHODS

PARTICIPANTS

Participants included 30 parents of children with ASD younger than 12 yrs and 36 parents of physically and mentally healthy children without any neurodevelopmental disorders as the TD control group. The diagnosis of ASD were made clinically by the child psychiatrist or attending paediatrician according to DSM5. Children with comorbidities such as ADHD and any other neurodevelopmental disorders were excluded from the study. The TD group was regarded as the control group on the basis that they were attending mainstream education according to their age and not attending any doctors for any developmental problems.

MATERIALS

Parenting Stress Index (PSI), 3rd Edition Short Form was used to assess the parents. PSI by (Abidin 1995) is a psychometric clinical assessment that consists of 36 items used to analyse relative magnitude of parenting stress based on three scales which are, parental distress (PSI/PD), parent-child dysfunctional interaction (PSI/P-CDI) and difficult child (PSI/DC). Total stress accounts for the stress reported for all the 3 areas, including parental distress, stress originated from the relationships and interactions between parent and child and the child (Abidin 1995). Parental Distress (PSI/PD) determines the distress a parent is undergoing in his or her role as a parent as a function of personal factors that are associated with

parenting. This includes inadequate social support, conflict with spouse, and stresses related to restrictions placed on other life roles (Abidin 1995). Parent-child dysfunctional interaction (PSI/P-CDI) highlights the parents' perception that his or her child is a negative element in their lives as their children do not meet their expectation or they are not accepted by their children (Abidin 1995). The domain of PSI/DC portrays the difficulty experienced by parents in managing challenging behavioural characteristics of their children (Abidin 1995). The PSI Malay version was used so that it could be comprehended by those samples who are illiterate in English. The PSI Malay version was validated and it showed that it was a reliable questionnaire to investigate the parenting stress levels among caregivers of children with learning disabilities (Nazurah et al. 2015). Demographic data of samples were collected including age and sex for both parents and their children, ethnic group, marital status, education background, employment status, number of children, and presence of any caregiver. Parents undergoing intervention were also recorded.

PROCEDURE

After obtaining Universiti Kebangsaan Malaysia (UKM) Ethics Committee approval and written consent from the parents, samples were collected from the UKM Child Psychiatric Clinic (27%) and Tangkak Hospital (23%) while the parents were bringing their children for regular medical check-up. Some samples were also taken from the

National Autism Society of Malaysia (NASOM) in Muar (20%) and Segamat (30%). All the participants completed the assessment in 15 and 20 mins. Samples referred to researcher when they encountered terms and statements that they could not understand. After completion, the scores for each of the domain were calculated. The results were recorded using Statistical Package for Social Science (SPSS) Version 21st by the IBM Corporation at New York, United States. A summary of social demographic variables was done using descriptive analysis of frequencies. The relationship between scores of various domains in PSI and sociodemographic variables as independent variables were analysed using cross-tabulation analysis. All the variables were transformed by labeling into categorical variables. Chi-square with Fischer-exact test was used to test for statistical significance.

The scores were also compared using Whitney Mann U test if the variables were not normally distributed based on the Shapiro-Wilk Normality Test.

RESULTS

SOCIO-DEMOGRAPHIC BACKGROUND

A total of 30 parents of children with ASD and 36 parents of TD children were recruited. The samples were collected from the UKM Child Psychiatric Clinic (27%), Tangkak Hospital (23%), NASOM in Muar (20%) and Segamat (30%). All the subjects recruited met the inclusion criteria and completed the PSI questionnaire. Subjects between the two groups were matched by age, sex of parents, ethnic group and marital status. The sociodemographic profiles are summarized in Table 1.

Table 1: Socio-demographic data of subjects

Socio-Demographic	ASD (n=30) n (%)	Typical Development (TD) (n=36) n (%)
Parent Role		
Father	18 (60)	18 (50)
Mother	12 (40)	18 (50)
Ethnic		
Malay	20 (66.67)	25 (69.44)
Chinese	7 (23.33)	11 (30.56)
Indian	2 (6.67)	0 (0.00)
Others	1 (3.33)	0 (0.00)
Sex of Child		
Boys	18 (60)	18 (50)
Girls	12 (40)	18 (50)
Marital Status		
Married	30 (100)	36 (100)
Not Married (Single Parents)	0 (0)	0 (0)

The Chi-square with Fischer-exact tests results of all the subscales of PSI between the ASD group and the TD control group are shown in Table 2. The score of PSI Defensive Responding (PSIDR) shows that most of the samples (95.5%) in this study did not show defensive responding while answering the PSI. There was a significant difference in total stress ($p < 0.001$) between ASD group and TD control

group as the ASD group showed extremely high levels of total parenting stress compared to TD group. Regarding the subscale of Parental Distress (PSI/PD), significant difference ($p < 0.001$) was recorded with higher number of samples in the ASD group scored at the highest percentile (85 to 99th+ percentile) compared to TD control group. For the domain of Parent-Child Dysfunctional Interaction (PSI/P-CDI),

Table 2: Parenting stress levels between ASD group and typical development (TD) control group

	ASD (n=30) n (%)	Typical Development (TD) (n=36) n (%)	p Value
Defensive Responding (PSIDR) (Scores)			
10 and below	30 (100)	33 (91.67)	<0.001
10 and above	0 (0)	3 (8.33)	
Total Stress (Scores)			
86 and above	24 (80)	1 (2.78)	<0.001
70 – 85	6 (20)	11 (30.56)	
56 -69	0 (0)	12 (33.33)	
1-55	0 (0)	12 (33.33)	
Parental Distress (PSI/PD) (Scores)			
33 above	11 (36.67)	1 (2.78)	<0.001
26 – 32	16 (53.33)	10 (27.78)	
20 – 25	2 (6.67)	15 (41.67)	
1 – 19	1 (3.33)	10 (27.78)	
Parent-Child Dysfunctional Interaction (PSI/P-CDI) (Scores)			
26 above	28 (93.33)	3 (8.33)	<0.001
20 – 25	1 (3.33)	17 (47.22)	
14 - 19	1 (3.33)	15 (41.67)	
1 – 13	0 (0.00)	1 (2.78)	
Difficult Child (PSI/DC) (Scores)			
33 above	20 (66.67)	0 (0.00)	<0.001
26 – 32	8 (26.67)	3 (8.33)	
19 – 25	2 (6.67)	23 (63.89)	
1 – 18	0 (0.00)	10 (27.77)	

there was also a significant difference ($p < 0.001$) between these two groups in which there were higher number of samples in ASD group scored at the highest percentile compared to TD control group. Regarding the last subscale which is Difficult Child (PSI/DC), a significant difference ($p < 0.001$) was shown with significantly higher number of samples in the ASD group scored at the highest percentile compared to TD group. Since all the 4 domains, Total Stress, PSI/PD, PSI/P-CDI, PSI/DC and PSI/DC were not normally distributed based on Shapiro-Wilk Normality Test, the scores were also compared using Mann Whitney U Test. From results in Table 3, it shows that Total Stress, PSI/PD, PSI/P-CDI, and PSI/DC in the ASD group was statistically significantly higher than the TD group ($U = 169.5, p < 0.001$; $U = 81.0, p < 0.001$; $U = 41.0, p < 0.001$; $U = 51.0, p < 0.001$, respectively).

Parenting stress was also compared between sex of parents of children with ASD. For all the subscales of PSI/PD, PSI/P-CDI and PSI/DC, percentage of mothers scored at the highest percentile was slightly higher compared to fathers. However, there was no significant difference ($p = 1.000, p = 0.833, p = 0.767,$

and $p = 0.667$) for all the subscales (Total Stress, PSI/PD, PSI/P-CDI, and PSI/DC respectively). Since all the 4 domains, Total Stress, PSI/PD, PSI/P-CDI, PSI/DC and PSI/DC were not normally distributed based on Shapiro-Wilk Normality Test, the scores were also compared using Mann Whitney U Test. From the results, it was shown that PSI/P-CDI, and PSI/DC in the mother group was slightly higher than the father group with no significance difference ($U = 100.0, p = 0.767$; $U = 84.5, p = 0.667,$ respectively).

Parenting stress was also compared between parents of children with ASD of different age groups. The ASD children were divided into 2 age groups; a younger group of 1 to 7 yrs and an older group of 8 to 12 yrs. For the Total Stress and all the subscales of PSI/PD, PSI/P-CDI and PSI/DC, percentage of parents of older ASD children scored in the highest percentile was higher compared to parents of younger children with ASD. Similarly, there was no significant difference ($p = 0.651, p = 0.700, p = 1.000,$ and $p = 0.867$) for all the subscales (Total Stress, PSI/PD, PSI/P-CDI, and PSI/DC, respectively). Since all the 4 domains, Total Stress, PSI/PD, PSI/P-CDI, PSI/DC and PSI/DC

Table 3: Parenting stress levels between ASD group and typical development (TD) control group (Mann Whitney U Test)

	ASD Mean Rank (n=30)	Typical Development (TD) Mean Rank (n=36)	Mann Whitney U test
Total Stress (Scores)	49.80	19.92	169.5
Parental Distress (PSI/PD) (Scores)	45.85	23.21	81.0
Parent-Child Dysfunctional Interaction (PSI/P-CDI) (Scores)	48.80	20.75	41.0
Difficult Child (PSI/DC) (Scores)	50.13	19.64	51.0

were not normally distributed based on Shapiro-Wilk Normality Test, the scores were also compared using Mann Whitney U Test. From the results, it shows that Total Stress, PSI/PD, and PSI/DC in the elder age group was slightly higher than the younger age group with no significance difference (U=97.5, p=0.651; U=87.0, p=0.700; U=98.5, p=0.867, respectively).

Parenting stress was also compared between parents of male children of ASD and TD group. Table 4 shows the relative Chi-Square with Fischer-exact tests of Total Stress, PSI/PD, PSI/P-CDI,

and PSI/DC among parents of male children of ASD and TD group. There was a significant difference in Total Stress (p<0.001) between ASD group and TD control group as the ASD group showed extremely high levels of total parenting stress compared to TD group. Regarding the subscale of Parental Distress (PSI/PD), significant difference (p=0.001) was recorded with higher number of samples in the ASD group scored at the highest percentile (85 to 99th+ percentile) compared to TD control group. Regarding the domain of Parent-Child Dysfunctional Interaction

Table 4: Parenting stress levels between male children of ASD Group and typical development (TD) control group

	ASD (n=18) n (%)	Typical Development (TD) (n=18) n (%)	p Value
Total Stress (Scores)			
86 and above	15 (83.30)	1 (5.60)	<0.001
70 – 85	3 (16.70)	3 (16.70)	
56 -69	0 (0.00)	7 (38.90)	
1-55	0 (0.00)	7 (38.90)	
Parental Distress (PSI/PD) (Scores)			
33 above	6 (33.30)	1 (5.60)	<0.001
26 – 32	10 (55.60)	3 (16.70)	
20 – 25	1 (5.60)	8 (44.40)	
1 – 19	1 (5.60)	6 (33.30)	
Parent-Child Dysfunctional Interaction (PSI/P-CDI) (Scores)			
26 above	17 (94.40)	2 (11.10)	<0.001
20 – 25	1 (5.60)	7 (38.90)	
14 - 19	0 (0.00)	8 (44.40)	
1 – 13	0 (0.00)	1 (5.60)	
Difficult Child (PSI/DC) (Scores)			
33 above	12 (66.70)	0 (0.00)	<0.001
26 – 32	5 (27.80)	1 (5.60)	
19 – 25	1 (5.60)	12 (66.70)	
1 – 18	0 (0.00)	5 (27.80)	

(PSI/P-CDI), there was also a significant difference ($p < 0.001$) between these two groups in which there were higher number of samples in ASD group scored at the highest percentile compared to TD control group. Regarding the last subscale which is Difficult Child (PSI/DC), a significant difference ($p < 0.001$) was shown with significantly higher number of samples in the ASD group scored at the highest percentile compared to TD group. Since all the 4 domains, Total Stress, PSI/PD, PSI/P-CDI, PSI/DC and PSI/DC were not normally distributed based on Shapiro-Wilk Normality Test, the scores were also compared using Mann Whitney U Test. From results in Table 5, it shows that Total Stress, PSI/PD, PSI/P-CDI, and PSI/DC in the ASD group was statistically significantly higher than the TD group ($U = 15.0$, $p < 0.001$; $U = 51.0$, $p < 0.001$; $U = 22.5$, $p < 0.001$; $U = 9.5$, $p < 0.001$, respectively).

Parenting stress was compared between parents of female children of ASD and TD group. Table 6 shows the relative Chi-Square with Fischer-exact tests of Total Stress, PSI/PD, PSI/P-CDI, and PSI/DC among parents of female children of ASD and TD group. For all the subscales of Total Stress, PSI/PD,

PSI/P-CDI and PSI/DC, percentage of parents of female children of ASD group scored at the highest percentile was significantly higher compared to parents of female children of TD group. There was a significant difference ($p < 0.001$, $p = 0005$, $p < 0.001$, and $p < 0.001$) for all the subscales (Total Stress, PSI/PD, PSI/P-CDI, and PSI/DC, respectively). Since all the 4 domains, Total Stress, PSI/PD, PSI/P-CDI, PSI/DC and PSI/DC were not normally distributed based on Shapiro-Wilk Normality Test, the scores were also compared using Mann Whitney U Test. From results in Table 7, it shows that Total Stress, PSI/PD, PSI/P-CDI, and PSI/DC in the ASD group was statistically significantly higher than the TD group ($U = 12.0$, $p < 0.001$; $U = 31.5$, $p < 0.001$; $U = 20.0$, $p < 0.001$; $U = 10.5$, $p < 0.001$, respectively).

DISCUSSION

Autism Spectrum Disorder (ASD) has been associated with higher levels of parenting stress in relation to parents of children with other disabilities and parents of TD children. Parenting stress is one of the dominant aspect of research nowadays as ASD has become more prevalent in the society. Based

Table 5: Parenting stress levels between male children of ASD group and typical development (TD) control group (Mann Whitney U Test)

	ASD Group Mean Rank (n=18)	TD Group Mean Rank (n=18)	Mann Whitney U test
Total Stress (Scores)	26.67	10.33	15.0
Parental Distress (PSI/PD) (Scores)	24.67	12.33	51.0
Parent-Child Dysfunctional Interaction (PSI/P-CDI) (Scores)	26.25	10.75	22.5
Difficult Child (PSI/DC) (Scores)	26.97	10.03	9.5

Table 6: Parenting stress levels between female children of ASD group and typical development (TD) control group

	ASD (n=12) n (%)	Typical Development (TD) (n=18) n (%)	p Value
Total Stress (Scores)			
86 and above	9 (75.00)	0 (0.00)	<0.001
70 – 85	3 (25.00)	8 (44.00)	
56 -69	0 (0.00)	5 (27.80)	
1-55	0 (0.00)	5 (27.80)	
Parental Distress (PSI/PD) (Scores)			
33 above	5 (41.70)	0 (0.00)	<0.001
26 – 32	6 (50.00)	7 (38.90)	
20 – 25	1 (8.30)	7 (38.90)	
1 – 19	0 (0.00)	4 (22.20)	
Parent-Child Dysfunctional Interaction (PSI/P-CDI) (Scores)			
26 above	11 (91.70)	1 (5.60)	<0.001
20 – 25	0 (0.00)	10 (55.60)	
14 - 19	1 (8.30)	7 (38.90)	
1 – 13	0 (0.00)	0 (0.00)	
Difficult Child (PSI/DC) (Scores)			
33 above	8 (66.70)	0 (0.00)	<0.001
26 – 32	3 (25.00)	2 (11.10)	
19 – 25	1 (8.30)	11 (61.10)	
1 – 18	0 (0.00)	5 (27.80)	

Table 7: Parenting stress levels between female children of ASD group and typical development (TD) control group (Mann Whitney U Test)

	ASD Group Mean Rank (n=12)	TD Group Mean Rank (n=18)	Mann Whitney U test
Total Stress (Scores)	23.50	10.17	12.0
Parental Distress (PSI/PD) (Scores)	21.88	11.25	31.5
Parent-Child Dysfunctional Interaction (PSI/P-CDI) (Scores)	22.83	10.61	20.0
Difficult Child (PSI/DC) (Scores)	23.63	10.08	10.5

on the Centre of Disease Control and Prevention, 1% of the world population is afflicted by ASD. Researchers have shown that the nature of ASD requires

extra caregiving demands from the parents that results in higher levels of parenting stress. A study done by Dumas et al. (1991), and his team showed that

parents of children with ASD showed statistically higher levels of parenting stress compared to groups of parents of children with Down Syndrome and also parents of TD children. Studies using different instruments other than PSI also gave similar results in which the study done by Schieve et al. (2007) found, parents of ASD children scored highest levels of stress and aggravation range (55%) compared to parents of children with other developmental problems (44%), parents of children with special healthcare needs (12%) and parents of TD children (11%). A total of 89% of them also rated that their ASD children were facing emotions, concentration and behaviour impairments.

The scale of Defensive Responding indicates the extent of the respondents was presenting the most favourable impression of themselves to cover up the level problems or levels of stress in the relationship between parents and children. Those respondents who scored extremely low scores in PSIDR indicates that one of the following; the parent was trying to under report their stress symptoms, or the respondent was not fully involved in child care and thus he or she was not experiencing obvious parenting stress or the last possibility was that the sample handled parenting responsibilities well and maintained a good relationship with others, including his or her spouse (Abidin 1995). Since most of the samples (95.5%) exceeded the range of PSIDR, this indirectly indicated that the respondents reflected on themselves and their true feelings when answering the self-rated questionnaire.

When comparing parents of children with ASD and the TD control group, significantly higher scores of parental distress was recorded. This could be attributed by the lack of social support in the society in which acceptance and knowledge regarding ASD is still insufficient among the population. The contrast between the child's appearance, which betrays no signs of disability, and his or her behaviour, which is perceived as abnormal and "strange", frequently puts parents in very unpleasant and difficult conditions (Portway & Johnson 2005). Social disapproval for the child's behaviour often leads to stigmatization, experience of shame for parents, and their exclusion from normal social activities (Farrugia 2009). Lack of knowledge and awareness about ASD cause the negative attitude of society towards children with ASD themselves and also their parents. Boyd (2002) finds that mothers can adapt with children with ASD with the assistance of informal social support. Unfortunately, this type of support is limited as the society often has the perception that parents are left to look after their children alone, deprived of help even from close family members if they encounter problems with the children's functioning or disabilities. Parents' social life is affected which takes a toll on rapport with relatives and friends due to obligation of child care (Farrugia 2009).

Parents of children with ASD also show elevated levels of dysfunctional interaction in between parents and children. In Asian countries, most of

the parents prioritise obedience and academic excellence of children and having a child with disability is indeed a big challenge for most of the parents. Weak academic skills among children with mental health problems is one of the parents' worries (Norhaniza et al. 2010). ASD children is characterised by cognitive impairments and their lower ability to learn and adapt new things definitely cannot meet expectations of most of the parents. ASD children have limited ability to initiate and maintain interaction with others (Volkmar et al. 2004). However, intellectual level of the child is not a determinant of deficits in language and communication skills as children with High Functioning Autism also experience significant problems in interpersonal relations. A study done by Davis and Carter (2008) on parents of newly-diagnosed children (ASD), parents were disturbed and burdened by impairments of social skills among their children. Similar results also shown by a research carried out (Tomanik et al. 2004) which reported that in mothers of children with pervasive developmental disorders consisting mainly of ASD, their children's inability to participate in communication with others had led to significant stress among them. Communication impairments among ASD children is one of the main factors their parents seek professional assistance (Charman & Baird 2002).

Parents of children with ASD also reported higher scores in the subscale of Difficult Child compared to TD control group. Child behaviour problems is one of the factors that contribute the most to parenting stress (Bishop et al. 2007; Herring et al. 2006; Tomanik

et al. 2004). Children with ASD with impaired adaptive functioning require extra care to assist them in daily tasks such as getting dressed, eating and daily hygiene. Besides, some ASD children have insomnia or sleeping difficulties in which they have problems in falling asleep, they have short sleeping time and they might wake up several times per night and this has brought their parents under extreme exhaustion due to their children's circadian rhythm (Goodlin-Jones et al. 2008). They also possess self-injury, aggressive and other destructive behaviour (Richman 2009). With the accumulation of such demands along with other behavioural problems, it is no surprise that mothers evaluated taking care of children with autism to be much harder than raising most children of the same age (Montes & Halterman 2008).

When comparing the parenting stress between fathers and mothers of ASD children, there is no significant difference. Mothers recorded slightly higher levels of parenting stress compared to fathers. To date, very few research compared the parenting stress levels between fathers and mothers. Similar results were shown by the research carried out by Pisula (2007) in which mothers of children with ASD scored higher stress levels compared to mothers of children with Down Syndrome. In Asian countries, most of the responsibilities of taking care of children lie on mothers. Women are considered more emotional when dealing with stressful conditions (Hassan & Inam 2013). Having to deal with working stress and their children's deficits could deteriorate the parenting

stress level among mothers as some of the mothers have to work besides taking care of their children. Parenting stress in mothers was related to child's social skills, while no such relationship was found in fathers (Baker-Ericzén et al. 2005).

Overall, parents of older ASD children recorded a higher total parenting stress compared to younger children of ASD. However, the parenting stress between parents of younger and older children with ASD was not significant. Like any other children, children with ASD also undergo puberty or adolescence. Impairments in social development and communication among youths with ASD become more apparent in adolescence. Adolescents with ASD often develop social anxiety due to their impairments socially and cognitively. Other than that, they also experience increase in hormone levels like other adolescents. The increase in androgen for males and estrogen for females indirectly leads to stress and anxiety and eventually aggravates the aggressive behavioural problems among them (Gillies & McArthur 2010). Parents may have to cope with these extra difficulties among their children with ASD as they grow older and this will stress them in their daily lives.

LIMITATIONS OF STUDY

There were few limitations that would affect the reliability and validity of the results. Due to time constraint, only a small sample size was used with a total of 66 parents recruited. Since the samples were taken only from few centres, we may not have generalized

the results of this study to all Malaysian parents of children with ASD. This study could be further strengthened by using a larger sample size so that it can give better results and samples should be collected randomly throughout the country.

CONCLUSION

Parents of children with ASD showed significantly higher levels of stress compared to parents of TD children. Intervention towards ASD children should not only focus on minimizing the core symptoms but should also pay attention to the family, as well. Special attention should be tendered towards the parents in which their mental and psychological health should not be overlooked.

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Received: 8 October 2016

Accepted: 29 May 2017