# Artikel Asli/Original Articles

# Perceived Stress among Malay Caregivers of Children with Learning Disabilities in Kelantan

# (Anggapan Stres dalam Kalangan Penjaga Melayu Anak-anak Bermasalah Pembelajaran di Kelantan)

SITI NOR ISMALINA ISA, ISMARULYUSDA ISHAK, AZRIANI AB RAHMAN, NUR ZAKIAH MOHD SAAT, NORMAH CHE DIN, SYARIF HUSIN LUBIS & MUHAMMAD FAIZ MOHD ISMAIL

# ABSTRACT

Parents or caregivers of children with learning disabilities have been shown to experience increases in stress and greater negative caregiving consequences than those with typically developing children. The current study sought to assess the perceived stress among Malay caregivers of children with learning disabilities in Kelantan. The Malay version of Perceived Stress Scale 10 items was administered to a sample of 40 caregivers of children with learning disabilities who were registered to five Pusat Pemulihan Dalam Komuniti (PDK) in Kelantan. Higher scores indicate higher levels of stress. The caregivers had mean age of 47.68 (SD = 9.18) years old, of whom 90% were fathers or mothers. Ninety percent of them were married, majority were unemployed or housewives and had secondary school education. The majority of children with learning disabilities were males and half of them were Down Syndrome children. The mean total Perceived Stress Scale score of the caregivers was 16.77 (SD = 5.74). There were no significant associations between total perceived stress score and any of the independent variables. The mean total perceived stress score showed that the perceived stress level was in the category of slightly higher than average and health concern level was high, while the average stress level was between score of 12 to 15. In conclusion, this result indicated that the caregivers had slightly higher levels of stress than the average score, and might increase susceptibility to stress-induced illness.

Keywords: Stress; caregivers; parents; children with learning disabilities

# ABSTRAK

Ibu bapa atau penjaga anak-anak bermasalah pembelajaran telah ditunjukkan mengalami peningkatan stress dan kesan negative penjagaan yang lebih besar berbanding mereka yang mempunyai anak-anak yang membesar dengan normal. Kajian ini adalah bertujuan untuk menilai anggapan stress dalam kalangan penjaga Melayu anak-anak bermasalah pembelajaran di Kelantan. Skala Anggapan Stres 10 item versi Bahasa Melayu telah diedarkan kepada satu sampel 40 penjaga anak-anak bermasalah pembelajaran yang berdaftar dengan lima Pusat Pemulihan Dalam Komuniti (PDK) di Kelantan. Skor yang lebih tinggi menunjukkan tahap stres yang lebih tinggi. Penjaga mempunyai min umur 47.68 (SD = 9.18) tahun, yang mana 90% ialah ayah atau ibu. Sembilan puluh peratus daripada mereka berkahwin, majority adalah tidak bekerja atau surirumah dan mempunyai pendidikan sekolah menengah. Majoriti anak-anak bermasalah pembelajaran tersebut ialah lelaki dan separuh daripada mereka merupakan anak-anak Sindrom Down. Min jumlah skor Skala Anggapan Stres penjaga ialah 16.77 (SD = 5.74). Tiada hubungan yang signifikan antara jumlah skor anggapan stress dan mana-mana pemboleh ubah bebas yang dikaji. Min jumlah skor anggapan stress telah menunjukkan tahap anggapan stress berada dalam kategori sedikit lebih tinggi daripada purata dan tahap kebimbangan kesihatan adalah tinggi, manakala tahap stress purata adalah di antara skor 12 hingga 15. Kesimpulannya, hasil ini telah menunjukkan kerentanan terhadap penyakit yang disebabkan stres.

Kata kunci: Stres; penjaga; ibu bapa; kanak-kanak bermasalah pembelajaran

# INTRODUCTION

The Department of Social Welfare Malaysia has defined learning disabilities as disorders in learning, cognition and intelligence that is inconsistent with the biological age. Children with learning disabilities include those who have global developmental delay (less than 5 years old), Down syndrome, autism spectrum disorders (ASD), attention deficit hyperactive disorder (ADHD), intellectual disability (more than 5 years old), and specific learning difficulties (dyslexia, dyscalculia and dysgraphia) (Jabatan Kebajikan Masyarakat, JKM 2013). General learning disability also must be differentiated from specific learning difficulty, which means that the person has specifically one difficulty such as in reading, writing, or solving mathematical problems, but has no problem with learning in other areas (Tidy 2013).

The World Report on Disability documented that more than one billion people in the world, which represented 15% of the global population, were living with some forms of disability (World Health Organization 2011). It has been estimated that 1.2 million people had learning disabilities in England in 2011, including 286,000 children aged 0 to 17 years (Tidy 2013). In the United States, about 4% of the students attending public schools are estimated to have specific learning disabilities (Dzalani & Shamsuddin 2014). In Malaysia, the prevalence of people with learning disabilities is on the rise. There were an increasing number of registered people with learning disabilities from 109, 708 in 2009 to 178, 800 in 2013. The Department of Social Welfare Malaysia reported that newly registered people with learning disabilities in 2013 was 13,519 including 6,526 children aged 18 years and below (JKM 2011, 2014).

Parenting a child with a learning disability is often stressful as the parents have to cope with many changing demands related to the specific needs of their child. Parents who have children with a learning disability need to give more focus on their daily care and learning activities as they have limitations in intellectual functioning, taking care of him or herself, and in adaptive and social skills (Alves et al. 2000). The stress is present across children's ages, from toddlerhood through middle childhood, adolescence, and into adulthood. Research findings showed that the level of parenting stress is higher in parents of children with learning disabilities than in parents of typically developing children (Dabrowska & Pisula 2010; Gallagher et al. 2010; Hoffman et al. 2009; Merkaj et al. 2013). A Malaysian study claimed that mothers of children with Down syndrome were also at risk of parenting stress. However, without a control group in the study, the level of parenting stress among the mothers of children with Down syndrome could not be concluded (Norizan & Shamsuddin 2010).

The stress experienced by parents of children with learning disability depends on multiple factors. Problematic and challenging behaviours in the children might be a main source of stress for caregivers of children with learning disabilities (Myers et al. 2009; Norizan & Shamsuddin 2010; Rezendes & Scarpa 2011; Tehee et al. 2009; Walsh et al. 2013). When a child engages in behaviour problem it can disrupt the entire family and make it more difficult to complete daily caregiving tasks, thus increasing parent stress surrounding those day-to-day tasks (Walsh et al. 2013). Previous studies found that mothers experienced more stressed and reported higher levels of stress and coping related to caregiving when compared with fathers (Dabrowska & Pisula 2010; Tehee et al. 2009). Mothers who are usually spent more time in caregiving for their children and tend to participate actively in their education may feel more burdened with their children's dependence on care than do fathers (Dabrowska & Pisula 2010).

Some other factors that were found to be associated with parental stress were marital status (Norizan & Shamsuddin 2010), parental coping strategies (Dabrowska & Pisula 2010; Norizan & Shamsuddin 2010; Walsh et al. 2013), and types of diagnosis of the children (Dabrowska & Pisula 2010; Rezendes & Scarpa 2011; Shobana & Saravanan 2014). Local research demonstrated that divorced or widowed mothers had higher parenting stress and lower parental and family functioning compared to married mothers (Norizan & Shamsuddin 2010; Isa et al. 2013). The literature also has shown that caregivers used a broad range of coping strategies and that there are indications that some strategies are more successful in some situations than in others. Dabrowska and Pisula (2010) reported that emotion-oriented coping was the predictor for parental stress in the parents of children with autism and Down syndrome, whereas task-oriented coping was the predictor of parental stress in the parents of typically developing children. Furthermore, some aspects of the impact of caregiving on the caregiver's health differ depending on the nature and severity of the children's illness. As for example, when compared with mothers of children with Down syndrome, parents of children with autism disorder exhibited higher scores on somatic symptoms, anxiety, social dysfunction, and negative attitudes (Shobana & Saravanan 2014), and higher level of stress (Dabrowska & Pisula 2010).

In fact, psychological distress following a diagnosis of childhood disability involves risks of long-term psychosocial problems for parents and families. Stressful situations experienced by caregivers of children with learning disability are considered to be crucial in determining the quality of life and family functioning of the families. According to Cramm and Nieboer (2011), parental stress is a strong predictor of caregivers' psychological well-being and usually results in decisions to place the children with intellectual disabilities in the care of others. Therefore, it is very important to recognize caregivers who experienced stress as it impacts not only their own psychological well-being but also their children's development and rehabilitation.

Despite the extensive knowledge on stress levels in parents of children with learning disabilities, such research remains understudied in non-Western populations, particularly in Malaysia. It is very important to recognize our caregivers who experienced stress in order to provide informational resources and support services that meet the needs of caregivers. In addition, the majority of international and local research has focused on stress among parents of children with specific age and diagnosis. The current study used sample of caregivers of a wider age group and diagnosis of individuals with learning disabilities to give an overview on their stress level. As Kelantan is recorded as the poorest state and has the lowest urbanization rate in Malaysia (Jabatan Statistik Malaysia 2011), it may predispose the caregivers to more unmet needs and socio-structural constraints which may lead them to psychological distress. Thus, the main aim of the present study was to assess the perceived stress among Malay caregivers of children with learning disabilities in Kelantan, Malaysia. This study also examined the relationships between perceived stress and parental socio-demographics and children characteristics variables. It is hypothesized that perceived stress in caregivers were different based on their gender, marital status, occupation, educational level, chronic illness, and child's gender, types of diagnosis and reported medical or health problems. This study also hypothesized that perceived stress were correlated with monthly household income, number of disabled children and number of children in the family, child's age, time since diagnosis, and care dependency.

# METHODOLOGY

#### STUDY DESIGN AND PARTICIPANTS

This pilot study was conducted in five community-based rehabilitation centers for the disabled people (Pusat Pemulihan Dalam Komuniti or PDK) under the authority of Department of Social Welfare Malaysia in four districts in Kelantan. This cross-sectional study was conducted in October to November 2014. The participants were 40 parents or caregivers who met the inclusion criteria as follows: (1) those who are primary caregivers; (2) have a child with diagnosis of Down syndrome, autism, attention-deficit hyperactive disorder (ADHD), global developmental delays, intellectual disability, or specific learning disabilities; (3) their child aged of 18 years old and below; and (4) their child lives at home. Caregivers who were absent during the study period and/or demonstrated a severe mental illness were excluded from the study.

#### PROCEDURES

This study was approved by the Universiti Kebangsaan Malaysia Research Ethics Committee and the Department of Social Welfare Malaysia. A self-administered and guided questionnaire which consisted of socio-demographics background of children and caregivers, disability related variables and the Perceived Stress Scale 10 items (PSS-10) was distributed to the eligible caregivers. A signed form confirming informed consent was obtained from caregivers who agreed to participate.

# MEASURES

#### BACKGROUND INFORMATION SHEET

Background Information sheet consists of sociodemographic characteristics of the caregivers and their children, and disability related variables of the child. Sociodemographic characteristics included age, relationship to the child, gender, marital status, occupation, educational level, number of children and disabled children, monthly household income, financial support received for the child and family per month, and chronic illness in the caregivers. Disability related variables included time since diagnosis (years), reported medical or health problems, types of diagnosis, and care dependency. Care dependency was defined as the number of life domains on which the child needs care (8 items - physical, mobility, eating and drinking, medication use, coping with devices/tools, entertaining, contact with other children, education). This scale ranges from 0-8, where 0 indicates the child does not need support, and score 8 indicates the child needs support on all domains (Hatzmann et al. 2009). The current study showed that this scale had good internal consistency reliability with Cronbach's alpha,  $\alpha = 0.86$ .

#### PERCEIVED STRESS SCALE 10 ITEMS (PSS-10)

The PSS-10, developed by Cohen et al. (1983), is the most widely used psychological instrument for measuring the perception of stress (Cohen et al. 1983). The questions in the PSS-10 ask about feelings and thoughts during the last month. The 10 items of PSS-10 were rated on five-point Likert scale based on the frequency of the stressful event experienced by the participant (0 = never, 1 = almost never, 2 = sometimes, 3 = fairly often, 4 = very often). The higher the score of the PSS-10, the higher the stress perceived by the participant. The previous study reported that the Malay version of PSS-10 had good internal consistency reliability with Cronbach's alpha coefficient was 0.78 for the total scale. Test-retest reliability analysis showed that the Malay version of the PSS-10 had an intraclass correlation coefficient (ICC) of 0.82 (95 % CI: 0.70, 0.89). It also had good factor loading values for all items which ranging from 0.67 to 0.84 (Al-Dubai et al. 2012). This present study also showed good internal consistency reliability of the Malay version of PSS-10 with Cronbach's alpha coefficient of 0.77.

#### STATISTICAL ANALYSIS

Data analysis was conducted using IBM SPSS 22.0 (IBM Corp., USA). The socio-demographic information, disability related variables, and perceived stress score were summarized using descriptive statistics. Results were presented as mean and standard deviation (SD) for numerical and normally distributed data. Median and inter-quartile range (IQR) were used to describe numerical variables which contained skewed data. Independent t-test and one-way ANOVA were applied to test significant differences of total perceived stress score between categorical independent variables (gender, marital status, occupation, educational level, chronic diseases, types of diagnosis, reported medical/health problems). Spearman's correlation was used to describe the strength and direction of associations between total perceived stress score and

continuous independent variables (age, number of disabled children, number of children, monthly household income, time since diagnosis and care dependency). The significant level was set at 0.05 significance two-tailed.

# RESULTS

# PROFILES OF CAREGIVERS AND CHILDREN WITH LEARNING DISABILITIES

Table 1 shows socio-demographic profiles of the caregivers who participated in this study. Majority of participants were fathers or mothers (90%), with two grandparents (5%) and two siblings (5%) of the child. The majority of the caregivers were female (80%). The age of the caregivers ranged from 29 years to 67 years with the mean of 47.68 (SD = 9.18) years. Almost all caregivers were married (90%), with two divorced and widowed, respectively. Most of the caregivers were unemployed or housewives (70%), 22.5% were self-employed, 5% were government employee and only 1 was private employee (2.5%). The educational level of 10 caregivers (25%) was low (having no formal or only primary school education) and the majority had secondary school education (70%). Their median monthly household income was Malaysian Ringgit (MYR) 900 (IQR = MYR 1400), with minimum and maximum income of MYR 150 and MYR 5770 respectively (USD 1 = MYR 4.25). The median financial support received per month from Department of Social Welfare or other organizations was MYR 150 (IOR = MYR 80). The majority of the caregivers indicated that they had one disabled child (85%). Thirteen of the participants had at least a chronic illness such as diabetes mellitus, hypertension or heart diseases.

The children with learning disabilities had mean age of 10.61 (SD = 5.60) years. The majority of them were boys (57.5%). Seventeen (42.5%) of them were reported to have other medical problems or comorbidities such as heart problems, epilepsy, asthma, or other impairments. Regarding the diagnosis, the majority of the children had Down syndrome (50%). Five children had autism (12.5%) and specific learning disabilities (12.5%) respectively. Others were children with ADHD (10%), intellectual disability (10%) and global developmental delay (5%). The mean time since diagnosis was 8.76 (SD = 5.11) years, and the mean care dependency was 37.23 (SD = 14.89) (Table 2).

#### PERCEIVED STRESS

Table 3 shows item level descriptive statistics of PSS-10. Each item mean ranging from 1.40 (item 6) to 2.08 (item 7). Most of the participants responded in the "sometimes" category for all 10 items of the scale (40% to 77.5%). Majority of the caregivers (77.5%) said that they sometimes had been upset because of something that happened unexpectedly. A good number of caregivers (20%) fairly often and often felt difficulties were piling up so high that

72

they could not overcome them. The mean total PSS-10 score of all 40 caregivers was 16.77 (SD = 5.74), with minimum score of 3.00 and maximum score of 26.00. The mean total perceived stress score was fall in the category of slightly higher than average and health concern level was high. Table 4 shows the interpretation of perceived stress level according to total PSS-10 score.

# ASSOCIATIONS BETWEEN PERCEIVED STRESS WITH PARENTAL AND CHILD CHARACTERISTICS

Table 5 presents the results of Independent t-test and one way ANOVA. The analyses revealed that there were no significant differences of mean total perceived stress score between gender of caregiver and child, marital status, occupation, educational level, chronic diseases, child's

TABLE 1. Socio-demographic characteristics of the caregivers (n = 40)

( <i>n</i> =	= 40)	
Characteristics	Mean (SD)	Frequency (%)
Age (years old) Number of children	47.68 (9.18) 5.39 (2.54)	
Number of disabled children One Two Three		34 (85.0) 2 (5.0) 4 (10.0)
Relationship to the children Father/Mother Grandfather/Grandmother Siblings		36 (90.0) 2 (5.0) 2 (5.0)
Gender Male Female		8 (20.0) 32 (80.0)
Marital status Married Single Divorced Widowed		36 (90.0) 0 (0.0) 2 (5.0) 2 (5.0)
Occupation Unemployed/Housewives Private employee Government employee Self-employed		28 (70.0) 1 (2.5) 2 (5.0) 9 (22.5)
Educational level No formal education Primary school Secondary school University/college		1 (2.5) 9 (22.5) 28 (70.0) 2 (5.0)
Monthly household income (MYR) Financial support received (MYR)	900.00 (1400.00) <sup>a</sup> 150.00 (80.00) <sup>a</sup>	
Chronic diseases No Yes		27 (67.5) 13 (32.5)

<sup>a</sup>Median (IQR)

Characteristics	Mean (SD)	Frequency (%)
Age (years old)	10.61 (5.60)	
Gender		
Boy		23 (57.5)
Girl		17 (42.5)
Reported medical/health problems		
No		23 (57.5)
Yes		17 (42.5)
Time since diagnosis (duration of disability) (years)	8.76 (5.11)	
Care dependency <sup>a</sup>	37.23 (14.89)	
Types of diagnosis:		
Down syndrome		20 (50.0)
ADHD		4 (10.0)
Autism		5 (12.5)
Global developmental delay		2 (5.0)
Intellectual disability		4 (10.0)
Specific learning disability		5 (12.5)

TABLE 2. Characteristics of the children with learning disabilities (n = 40)

<sup>a</sup>Scale 0-8 (high score representing high dependency); maximum score: 64

TABLE 3. Mean and distribution of responses for each of questions in the Malay version PSS-10 ( $n = 40$ )
--

	V.	M (CD)			n (%)		
	Items	Mean (SD)	Never	Almost never	Sometimes	Fairly often	Very often
1.	Dalam tempoh sebulan ini, berapa kerap anda marah disebabkan sesuatu itu berlaku tanpa anda jangka? In the last month, how often have you been upset because of something that happened unexpectedly?	1.93 (0.73)	3 (7.5)	2 (5.0)	31 (77.5)	3 (7.5)	1 (2.5)
2.	Dalam tempoh sebulan ini, berapa kerap anda merasakan bahawa anda tidak boleh mengawal sesuatu perkara yang penting dalam hidup anda? <i>In the last month, how often have you felt that you were unable to control</i> <i>the important things in your life</i> ?	1.45 (0.96)	9 (22.5)	8 (20.0)	19 (47.5)	4 (10.0)	0 (0.0)
3.	Dalam tempoh sebulan ini, berapa kerap anda berasa gementar dan tertekan? In the last month, how often have you felt nervous and "stressed"?	1.45 (0.96)	10 (25.0)	5 (12.5)	22 (55.0)	3 (7.5)	0 (0.0)
4.	Dalam tempoh sebulan ini, berapa kerap anda berasa yakin dengan kebolehan anda untuk mengurus masalah peribadi anda? In the last month, how often have you felt confident about your ability to handle your personal problems?	1.58 (0.96)	3 (7.5)	1 (2.5)	15 (37.5)	18 (45.0)	3 (7.5)
5.	Dalam tempoh sebulan ini, berapa kerap anda berasa bahawa perkara yang berlaku mengikut apa yang anda rancangkan? <i>In the last month, how often have you felt that things were going your way?</i>	1.95 (0.85)	3 (7.5)	3 (7.5)	24 (60.0)	9 (22.5)	1 (2.5)
6.	Dalam tempoh sebulan ini, berapa kerap anda dapati bahawa anda tidak boleh mengawal perasaan dengan semua perkara yang telah anda lakukan? <i>In the last month, how often have you found that you could not cope with all the things that you had to do?</i>	1.40 (1.01)	11 (27.5)	6 (15.0)	19 (47.5)	4 (10.0)	0 (0.0)
7.	Dalam tempoh sebulan ini, berapa kerap anda telah dapat mengawal ketidak selesaan dalam hidup anda? In the last month, how often have you been able to control irritations in your life?	2.08 (1.02)	5 (12.5)	4 (10.0)	23 (57.5)	5 (12.5)	3 (7.5)
8.	Dalam tempoh sebulan ini, berapa kerap anda berasa bahawa anda berjaya mengatasi semua masalah? In the last month, how often have you felt that you were on top of things?	1.70 (0.85)	2 (5.0)	3 (7.5)	17 (42.5)	17 (42.5)	1 (2.5)
9.	Dalam tempoh sebulan ini, berapa kerap anda telah marah disebabkan perkara yang berlaku di luar kawalan anda? In the last month, how often have you been angered because of things that were outside of your control?	1.85 (1.05)	5 (12.5)	8 (20.0)	17 (42.5)	8 (20.0)	2 (5.0)

Continued

TABLE 1. Continue

 		n (%)				
Items	Mean (SD)	Never	Almost never	Sometimes	Fairly often	Very often
10. Dalam tempoh sebulan ini, berapa kerap anda berasa kesusahan yang melampau sehingga anda tidak dapat mengatasinya? In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	1.63 (1.15)	9 (22.5)	7 (17.5)	16 (40.0)	6 (15.0)	2 (5.0)
Total score	16.77 (5.74)					

Total score

TABLE 4. Perceived stress and health concern level according to score

	10 50010	
Total	Perceived	Health Concern
Score	Stress Level	Level
0-7 8-11	Much lower than average Slightly lower than average	Very low Low
12-15	Average	Average
16-20	Slightly higher than average	High
21 and over	Much higher than average	Very high

(Source: Kelly & Percival (2010)

### TABLE 5. Mean difference of perceived stress score among caregiver's and child's characteristics

A. Caregiver characteristics       Gender         Male       17.00 (5.40)       1.000         Female       17.00 (5.62)       1.000         Marital status       Married       17.08 (5.46)       0.778         Not married       16.25 (6.80)       0.778       0.00         Occupation       Unemployed       17.75 (5.42)       0.192         Employed       15.25 (5.55)       0.192         Educational level       Low education       16.70 (7.13)       0.402         Secondary education       17.46 (4.86)       0.1746 (4.86)         University/college       12.00 (5.66)       0.764         No       17.19 (5.29)       0.764         B. Child characteristics       Gender       0.530         Male       17.48 (6.03)       0.530         Female       16.35 (4.82)       0.720         No       16.65 (5.52)       0.720         No       16.65 (5.52)       0.720         No       16.65 (5.52)       0.720	Variable	Mean (SD)	<i>p</i> value
Male Female $17.00 (5.40)$ $1.000$ Female $17.00 (5.62)$ $1.000$ Marital status Married $17.08 (5.46)$ $0.778$ Not married $16.25 (6.80)$ $0.000$ Occupation Unemployed $17.75 (5.42)$ $0.192$ Employed $15.25 (5.55)$ $0.192$ Educational level Low education $16.70 (7.13)$ $0.402$ Secondary education University/college $12.00 (5.66)$ $0.764$ Chronic diseases Yes No $16.62 (6.14)$ $0.764$ No $17.19 (5.29)$ $0.530$ B. Child characteristics Gender Male $17.48 (6.03)$ $0.530$ Female $16.35 (4.82)$ $0.720$ No $16.65 (5.52)$ $0.720$ Types of diagnosis $0.720$			
Female       17.00 (5.62)         Marital status       Married         Married       17.08 (5.46)       0.778         Not married       16.25 (6.80)       0.778         Occupation       16.25 (5.80)       0.192         Employed       17.75 (5.42)       0.192         Employed       15.25 (5.55)       0.192         Educational level       Low education       16.70 (7.13)       0.402         Secondary education       17.46 (4.86)       0.192         University/college       12.00 (5.66)       0.192         Chronic diseases       Yes       16.62 (6.14)       0.764         No       17.19 (5.29)       0.530         B. Child characteristics       Gender       16.35 (4.82)         Reported medical/health       problems       16.35 (4.82)         Reported medical/health       problems       0.720         No       16.65 (5.52)       0.720         Types of diagnosis       17.31 (5.77)       0.720	Gender		
Marital status       Married       17.08 (5.46)       0.778         Not married       16.25 (6.80)       0.778         Occupation       16.25 (6.80)       0.192         Employed       17.75 (5.42)       0.192         Employed       15.25 (5.55)       0.192         Educational level       16.70 (7.13)       0.402         Secondary education       17.46 (4.86)       0.192         University/college       12.00 (5.66)       0.192         Chronic diseases       12.00 (5.66)       0.778         Yes       16.62 (6.14)       0.764         No       17.19 (5.29)       0.192         B. Child characteristics       Gender       16.35 (4.82)         Reported medical/health       16.35 (4.82)       0.530         Female       16.35 (5.52)       0.720         No       16.65 (5.52)       0.720         No       16.65 (5.52)       0.720	111110		1.000
Married       17.08 (5.46)       0.778         Not married       16.25 (6.80)       0         Occupation       16.25 (6.80)       0.192         Unemployed       17.75 (5.42)       0.192         Employed       15.25 (5.55)       0         Educational level       16.70 (7.13)       0.402         Secondary education       17.46 (4.86)       0         University/college       12.00 (5.66)       0         Chronic diseases       Yes       16.62 (6.14)       0.764         No       17.19 (5.29)       0       0         B. Child characteristics       Gender       0.530         Male       17.48 (6.03)       0.530         Female       16.35 (4.82)       0         Reported medical/health       problems       Yes       17.31 (5.77)       0.720         No       16.65 (5.52)       Types of diagnosis       0       0       0       0	Female	17.00 (5.62)	
Not married         16.25 (6.80)           Occupation         17.75 (5.42)         0.192           Employed         15.25 (5.55)         0.192           Educational level         16.70 (7.13)         0.402           Low education         16.70 (7.13)         0.402           Secondary education         17.46 (4.86)         0.192           University/college         12.00 (5.66)         0           Chronic diseases         Yes         16.62 (6.14)         0.764           No         17.19 (5.29)         0         0           B. Child characteristics         Gender         16.35 (4.82)         0.530           Female         16.35 (4.82)         0.720         0           No         16.65 (5.52)         0         0.720           Types of diagnosis         17.31 (5.77)         0.720	Marital status		
Occupation         17.75 (5.42)         0.192           Employed         15.25 (5.55)         0.192           Educational level         15.25 (5.55)         0.402           Low education         16.70 (7.13)         0.402           Secondary education         17.46 (4.86)         0.192           University/college         12.00 (5.66)         0.402           Chronic diseases         Yes         16.62 (6.14)         0.764           No         17.19 (5.29)         0.764           B. Child characteristics         Gender         0.530           Female         16.35 (4.82)         0.530           Female         16.35 (4.82)         0.720           No         17.31 (5.77)         0.720           No         16.65 (5.52)         0.720	Married	17.08 (5.46)	0.778
Unemployed Employed         17.75 (5.42) 15.25 (5.55)         0.192           Educational level Low education         16.70 (7.13) 17.46 (4.86)         0.402           Secondary education University/college         12.00 (5.66)         0.402           Chronic diseases Yes         16.62 (6.14) No         0.764           No         17.19 (5.29)         0.764           B. Child characteristics Gender Male         17.48 (6.03) I6.35 (4.82)         0.530           Reported medical/health problems         16.35 (4.82)         0.720           No         16.65 (5.52)         0.720           Types of diagnosis         17.31 (5.77)         0.720	Not married	16.25 (6.80)	
Employed       15.25 (5.55)         Educational level       16.70 (7.13)       0.402         Low education       17.46 (4.86)       0.17.46 (4.86)         University/college       12.00 (5.66)       0.764         No       17.19 (5.29)       0.764         B. Child characteristics       Gender       0.530         Male       17.48 (6.03)       0.530         Female       16.35 (4.82)       0.720         No       17.31 (5.77)       0.720         No       16.65 (5.52)       Types of diagnosis	Occupation		
Educational level       Low education $16.70 (7.13)$ $0.402$ Secondary education $17.46 (4.86)$ $12.00 (5.66)$ University/college $12.00 (5.66)$ Chronic diseases $Yes$ $16.62 (6.14)$ $0.764$ No $17.19 (5.29)$ $0.764$ B. Child characteristics       Gender $Male$ $17.48 (6.03)$ $0.530$ Female $16.35 (4.82)$ Reported medical/health $17.31 (5.77)$ $0.720$ No $16.65 (5.52)$ Types of diagnosis	Unemployed	17.75 (5.42)	0.192
Low education       16.70 (7.13)       0.402         Secondary education       17.46 (4.86)         University/college       12.00 (5.66)         Chronic diseases       16.62 (6.14)         Yes       16.62 (6.14)       0.764         No       17.19 (5.29)       0.530         B. Child characteristics       Gender       16.35 (4.82)         Reported medical/health       16.35 (4.82)       0.720         No       16.65 (5.52)       0.720         Types of diagnosis       17.31 (5.77)       0.720	Employed	15.25 (5.55)	
Secondary education University/college         17.46 (4.86)           University/college         12.00 (5.66)           Chronic diseases Yes         16.62 (6.14)         0.764           No         17.19 (5.29)         0.764           B. Child characteristics Gender         16.35 (4.82)         0.530           Female         16.35 (4.82)         0.530           Reported medical/health problems         17.31 (5.77)         0.720           No         16.65 (5.52)         17	Educational level		
Secondary education University/college         17.46 (4.86)           Chronic diseases Yes         12.00 (5.66)           Chronic diseases Yes         16.62 (6.14)         0.764           No         17.19 (5.29)         0.764           B. Child characteristics Gender         17.48 (6.03)         0.530           Female         16.35 (4.82)         0.530           Reported medical/health problems         17.31 (5.77)         0.720           No         16.65 (5.52)         1731	Low education	16.70 (7.13)	0.402
University/college         12.00 (5.66)           Chronic diseases         Yes           Yes         16.62 (6.14)         0.764           No         17.19 (5.29)         0.764           B. Child characteristics         Gender         0.730           Male         17.48 (6.03)         0.530           Female         16.35 (4.82)         0.530           Reported medical/health         problems         748           Yes         17.31 (5.77)         0.720           No         16.65 (5.52)         179pes of diagnosis	Secondary education		
Yes         16.62 (6.14)         0.764           No         17.19 (5.29)         0.764           B. Child characteristics         Gender         0.530           Male         17.48 (6.03)         0.530           Female         16.35 (4.82)         0.530           Reported medical/health         16.35 (4.82)         0.720           No         16.65 (5.52)         0.720           Types of diagnosis         17.31 (5.77)         0.720		12.00 (5.66)	
Yes         16.62 (6.14)         0.764           No         17.19 (5.29)         0.764           B. Child characteristics         Gender         0.530           Male         17.48 (6.03)         0.530           Female         16.35 (4.82)         0.530           Reported medical/health         16.35 (4.82)         0.720           No         16.65 (5.52)         0.720           Types of diagnosis         17.31 (5.77)         0.720	Chronic diseases		
No         17.19 (5.29)           B. Child characteristics Gender         17.48 (6.03)         0.530           Male         17.48 (6.03)         0.530           Female         16.35 (4.82)         16.35 (4.82)           Reported medical/health problems         17.31 (5.77)         0.720           No         16.65 (5.52)         15.55		16.62 (6.14)	0.764
Gender         17.48 (6.03)         0.530           Female         16.35 (4.82)           Reported medical/health         17.31 (5.77)         0.720           No         16.65 (5.52)	No		
Male         17.48 (6.03)         0.530           Female         16.35 (4.82)           Reported medical/health         16.35 (4.82)           Yes         17.31 (5.77)         0.720           No         16.65 (5.52)           Types of diagnosis         16.65 (5.52)	B. Child characteristics		
Female         16.35 (4.82)           Reported medical/health         16.35 (4.82)           problems         17.31 (5.77)           Yes         17.31 (5.77)           No         16.65 (5.52)	Gender		
Female         16.35 (4.82)           Reported medical/health         16.35 (4.82)           problems         17.31 (5.77)           Yes         17.31 (5.77)           No         16.65 (5.52)	Male	17.48 (6.03)	0.530
problems Yes 17.31 (5.77) 0.720 No 16.65 (5.52) Types of diagnosis	Female	16.35 (4.82)	
Yes 17.31 (5.77) 0.720 No 16.65 (5.52) Types of diagnosis	Reported medical/health		
No 16.65 (5.52) Types of diagnosis	problems		
Types of diagnosis	Yes		0.720
	No	16.65 (5.52)	
Down sundromo $17.00(6.14) = 0.042$	Types of diagnosis		
Down syndrome 17.00 (6.14) 0.943	Down syndrome	17.00 (6.14)	0.943
ADHD 18.25 (6.02)			
Autism 17.20 (3.56)			
Global developmental delay 13.50 (7.78)			
Intellectual disability 16.00 (4.69)			
Specific learning disability 18.00 (5.96)	Specific learning disability	18.00 (5.96)	

reported medical/health problems and types of diagnosis (p > 0.05). Correlation analysis showed perceived stress score had poor, positive and non-significant correlation with number of children in the family ( $r_s = 0.216$ ), monthly household income ( $r_s = 0.016$ ), and child's age ( $r_s =$ 0.018). Negative, low and non-significant correlation were observed between perceived stress and number of disabled children ( $r_s = -0.258$ ), time since diagnosis ( $r_s = -0.151$ ), and care dependency ( $r_s = -0.236$ ). Results of correlation analysis are shown in Table 6.

TABLE 6. Correlation between perceived stress and caregiver's and child's characteristics

Variable	Spearman's correlation coefficient $(r_s)$	<i>p</i> value
A. Caregiver characteristics		
Number of disabled children	-0.258	0.108
Number of children	0.216	0.181
Monthly household income	0.016	0.930
B. Child characteristics		
Age	0.018	0.911
Time since diagnosis	-0.151	0.371
Care dependency	-0.236	0.149

# DISCUSSION

The sample of caregivers of children with learning disabilities in this study appeared consistent with the caregivers described in previous research. Majority of the caregivers were the children's biological parents. Similar to most of the studies, a large number of the participants were mothers who are the primary caregiver of the children (Hsieh et al. 2009; Hu et al. 2011; Isa et al. 2013). This also showed that it is often the mother who forms a vital link between the child and health care professionals rather than father. Most of the participants were unemployed or housewives, had secondary school education and had median monthly household income of RM900. Their median monthly household income was slightly above the poverty line income for Peninsular Malaysia which was RM760 (Jala 2015). These demographics could suggest that most of the caregivers still came from low socio-economic status background.

In the current study, the level of perceived stress among the caregivers was slightly higher than average (Table 4), indicating that the caregivers of children with learning disabilities in Kelantan experienced stress. Interestingly, this study also observed a good number of caregivers fairly often and often felt difficulties were piling up so high that they could not overcome the difficulties. Further explanation by some caregivers revealed that the difficulties they faced mostly in terms of financial problems that lead to stress. Our finding was consistent with findings from previous studies that found parents of individuals with learning disabilities to be under considerable stress (Dabrowska & Pisula 2010; Gallagher et al. 2010; Hoffman et al. 2009; Merkaj et al. 2013; Norizan & Shamsuddin 2010). However, the perceived stress level in the current study was only made according to the PSS-10 scoring interpretation by Kelly and Percival (2010). Without a control or comparison group, it is difficult to draw any firm conclusion about the level of parenting stress among this group of caregivers.

Furthermore, this present study did not find any significant relationships of perceived stress with parental and children characteristics variables (Dabrowska & Pisula 2010; Myers et al. 2009; Norizan & Shamsuddin 2010; Rezendes & Scarpa 2011; Shobana & Saravanan 2014; Tehee et al. 2009; Walsh et al. 2013). In contrast with the past evidences that the mothers experienced higher levels of stress than fathers (Dabrowska & Pisula 2010; Tehee et al. 2009), this study found no differences in the mean perceived stress scores between males and females caregivers. In this study, perceived stress also was not statistically significantly associated with caregiver's marital status, chronic diseases, and socio-economic status (i.e. occupation, educational level and income). Positive correlation was observed between perceived stress and number of children in the family which is similar to previous studies that found the more number of children they had, the higher the level of stress and anxiety of the parents (Bumin et al. 2008; Dabrowska & Pisula 2010). Dabrowska and Pisula (2010) suggested that raising typically developing children along with a child with developmental disabilities may also increase the burdens experienced by parents and contribute to a higher level of stress. However, all the correlations in the current study were very low (r < 0.3) as well as not significant.

With regards to child's characteristics, the current study also showed no significant associations between perceived stress and child's demographic and disability related variables. The stress faced by parents was not statistically significantly different by the different types of children's diagnosis. This finding was contradict with earlier studies that found parents of children with autism disorder exhibited higher levels of stress and psychosomatic symptoms than parents of children with Down syndrome and intellectual disability (Dabrowska & Pisula 2010; Shobana & Saravanan 2014). Previous literature demonstrated that comorbid conditions in the children with learning disabilities were statistically associated with worse parental and family functioning (Limbers et al. 2011). However, the current study reported similar finding with Norizan and Shamsuddin (2010) that the stress was not significantly different by reported medical or health problems. Correlation analysis also showed perceived stress score had non-significant and weak correlation with child's age, time since diagnosis and care dependency.

The current study has some methodological weaknesses that limit its validity and reliability. Main possible reason for the non-significant results and low correlation found in this study might be due to the minimum required sample size was not achieved to meet the significance level. Basically, this study was a small study aimed to test logistics and assess the reliability and validity of the instrument. Larger sample sizes are needed for subgroup analyses in observational studies. The small sample size may fail the study to detect important effects or associations, or may lead to misleading results (Naing 2008). Small sample size may also limit the generalization of this study to all Malay caregivers of learning disabilities in Malaysia. Therefore, future research need to involve a large sample size in order to obtain the results of clinically meaningful differences that are also statistically significant, thus it can be generalized to the population.

Other possible reason for the non-significant finding could be resulting from problems with the measures of variables in this study. For example, income in this study was measured based on caregivers' reported of their gross monthly household income and this may not reflect the true income status of the family. Thus, the effect of income on the caregiver's stress could not be well measured. It is also important to note that assessment of the current study was based upon caregivers' self-report and some of them who were illiterate were interviewed, which the results might be biased by individual response styles or social desirability. Future research should seek the solutions to encounter the problems with measuring socio-economic status and disability related variables. The assessments also should not rely exclusively on caregivers' self-report, for example, the other alternatives would be to measure children's diagnosis and comorbidities are by medical records and/or psychometric testing. In-depth interviews, spouse's perception, or other-reported parenting responses should also be included to measure caregiver's stress.

Various other factors may contribute to vulnerability of the caregiver to psychological distress in different population instead of the variables explored in the current study. Other factors such as severity of disability, child behavioural problems, parental coping styles, formal and informal supports, parental attitude which were not accounted in this study, should be looked into more deeply in the future studies in order to discover the significant factors toward perceived stress among caregivers of children with learning disabilities in our culture. In addition, in the absence of data from caregivers of normally developing children, it is not possible to tell if these caregivers of children with learning disabilities would have been significantly more stressed than caregivers of 'normal' children. It would have been better if further study can be conducted involving a group of families with normal children or different illness, thus comparison could be made from the findings between different groups. Therefore, more valid and reliable conclusion could be drawn.

# CONCLUSION

In conclusion, caregivers of children with learning disabilities in Kelantan had slightly higher levels of stress than the average. Higher stress level in the caregivers might increase susceptibility to stress-induced illness and affect the adjustment to taking care of their child with learning disability. Despite the study limitations, this preliminary data should provide initial insights to the communities and increases the society awareness on the level of psychological distress experienced by the persons raising the children with learning disabilities in Kelantan. This study indicates the future research directions and draws implications for improving the quality of life of families of children with learning disabilities in our setting. This group of caregivers needs more concern by health professionals and policy makers. The healthcare and social service providers in this country must endeavour to improve current programmes and resources to the children with learning disabilities and their families. Financial resources, medical services, education, and social supports provided by government and non-governmental organizations to the children with learning disabilities in this state should be improved to assist the caregivers in encountering their obstacles. In addition, individualized intervention measures that are sensitive to the needs of the families and their children with learning disabilities are vital in order to help them to reduce their psychological distress.

#### ACKNOWLEDGEMENT

We would like to acknowledge the financial support from Fundamental Research Grant Scheme (FRGS) (Grant No.: FRGS/2/2014/SS02/UKM/02/2) of the Ministry of Higher Education. Special thanks went to all caregivers and teachers at PDK in Kelantan for their cooperation in this study.

# REFERENCES

- Al-Dubai, S.A.R., Alshagga, M.A., Rampal, K.G. & Sulaiman, N.A. 2012. Factor structure and reliability of the Malay version of the Perceived Stress Scale among Malaysian medical students. *Malaysian Journal of Medical Sciences* 19(3): 43-49.
- Alves, E., Bankhead, I., Baum, S., Leyin, A., Richens, A. & Samuel, J. 2000. *Learning Disability: Definitions and Contexts*. Leicester: The British Psychological Society.

- Bumin, G., Gunal, A. & Tukel, S. 2008. Anxiety, depression and quality of life in mothers of disabled children. S.D. Ü. TýpFak. Derg 15: 6-11.
- Cohen, S., Kamarck, T. & Mermelstein, R. 1983. A global measure of perceived stress. *Journal of Health & Social Behavior* 24: 386-396.
- Cramm, J.M. & Nieboer, A.P. 2011. Psychological well-being of caregivers of children with intellectual disabilities: Using parental stress as a mediating factor. *Journal of Intellectual Disabilities* 15(2): 101-113.
- Dabrowska, A. & Pisula, E. 2010. Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research* 54(3): 266-280.
- Dzalani, H. & Shamsuddin, K. 2014. A review of definitions and identifications of specific learning disabilities in Malaysia and challenges in provision of services. *Pertanika Journal* of Social Sciences & Humanities 22(1): 1-18.
- Gallagher, S., Phillips, A.C. & Carroll, D. 2010. Parental stress is associated with poor sleep quality in parents caring for children with developmental disabilities. *Journal of Pediatric Psychology* 35(7): 728-737.
- Hoffman, C.D., Sweeney, D.P., Hodge, D., Lopez-Wagner, M.C. & Looney, L. 2009. Parenting stress and closeness: Mothers of typically developing children and mothers of children with autism. *Focus on Autism and Other Developmental Disabilities* 24(3): 178-187.
- Hsieh, R.L., Huang, H.Y., Lin, M.I., Wu, C.W. & Lee, W.C. 2009. Quality of life, health satisfaction and family impact on caregivers of children with developmental delays. *Child: Care, Health & Development* 35(2): 243-249.
- Hu, X., Wang, M. & Fei, X. 2011. Family quality of life of Chinese families of children with intellectual disabilities. *Journal of Intellectual Disability Research*.
- Isa, S.N.I., Abd Aziz, A., Ab Rahman, A., Ibrahim, M.I., Wan Ibrahim, W.P., Mohamad, N., Othman, A., Abd Rahman, N., Harith, S. & Van Rostenberghe, H. 2013. The impact of disabled children on parent health-related quality of life and family functioning in Kelantan and its associated factors. *Journal of Developmental & Behavioural Pediatrics* 34(4): 262-268.
- Jabatan Kebajikan Masyarakat. 2013. *Pendaftaran Orang Kurang Upaya*. http://www.jkm.gov.my/content.php? pagename=pendaftaran\_orang\_kurang\_upaya&lang=bm [Final accessed on 1 November 2014].
- Jabatan Kebajikan Masyarakat. 2014. Laporan Statistik 2013. Bahagian B 10: Pendaftaran Orang Kurang Upaya. http://www.jkm.gov.my/content.php?pagename = statistik\_2013&lang=bm [Final accessed 11 October 2014].
- Jabatan Kebajikan Masyarakat. 2011. Laporan Statistik 2009. Bahagian B 10: Pendaftaran Orang Kurang Upaya. http://www.jkm.gov.my/content.php?pagename =statistik\_2009&lang=bm [Final accessed 1 August 2011].
- Jabatan Statistik Malaysia. 2011. Population and housing census of Malaysia 2010: Population distribution and basic demographic characteristics. http://www.statistics. gov.my/portal/download\_Population/files/census2010/ Taburan\_Penduduk\_dan\_Ciri-ciri\_Asas\_Demografi.pdf. [Final accessed 30 December 2013].

- Jala, I. 2015. *The measure of poverty*. http://etp.pemandu.gov.my/ Transformation\_Unplugged- @-The\_measure\_of\_poverty. aspx [ Final accessed on 3 August 2015].
- Kelly, G. & Percival, M. 2010. Perceived Stress Scale. http:// healthsceneinvestigation.com/files/2010/07/Percived-Stress-Scale.pdf. [Final accessed 1 May 2015].
- Limbers, C.A., Ripperger-Suhler, J., Boutton, K., Ransom, D. & Varni, J.W. 2011. A comparative analysis of health-related quality of life and family impact between children with ADHD treated in a General Pediatric Clinic and a Psychiatric Clinic utilizing the PedsQL. *Journal of Attention Disorders* 15(5): 392-402.
- Merkaj, V., Kika, M. & Simaku, A. 2013. Symptoms of stress, depression and anxiety between parents of autistic children and parents of tipically developing children. *Academic Journal of Interdisciplinary Studies* 2(2): 345-352.
- Myers, B.J., Mackintosh, V.H. & Goin-Kochel, R.P. 2009. "My greatest joy and my greatest heart ache:" Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders* 3: 670-684.
- Naing, N.N. 2008. A Practical Guide on Determination of Sample Size in Health Sciences Research. Kelantan: Universiti Sains Malaysia.
- Norizan, A. & Shamsuddin, K. 2010. Predictors of parenting stress among Malaysian mothers of children with Down syndrome. *Journal of Intellectual Disability Research* 54(11): 992-1003.

Siti Nor Ismalina Isa Biomedical Science Programme, School of Diagnostic and Applied Health Sciences, Faculty of Health Sciences, Universiti Kebangsaan Malaysia, Jalan Raja Muda Abdul Aziz, 50300 Kuala Lumpur, Malaysia

Faculty of Health Sciences, Universiti Teknologi MARA, 42300 PuncakAlam, Selangor, Malaysia

Ismarulyusda Ishak Nur Zakiah Mohd Saat Syarif Husin Lubis Muhammad Faiz Mohd Ismail Biomedical Science Programme, School of Diagnostic and Applied Health Sciences, Faculty of Health Sciences, Universiti Kebangsaan Malaysia, Jalan Raja Muda Abdul Aziz, 50300 Kuala Lumpur, Malaysia

Corresponding author: Ismarulyusda Ishak Email address: ismarul@ukm.edu.my Telephone: +6019-225052 Fax: +603-2692 9032

Received: September 2015 Accepted for publication: March 2016

- Rezendes, D.L. & Scarpa, A. 2011. Associations between parental anxiety/depression and child behavior problems related to autism spectrum disorders: The roles of parenting stress and parenting self-efficacy. *Autism Research and Treatment*. DOI:10.1155/2011/395190
- Shobana, M. & Saravanan, C. 2014. Comparative study on attitudes and psychological problems of mothers towards their children with developmental disability. *East Asian Arch Psychiatry* 24: 16-22.
- Tehee, E., Honan, R. & Hevey, D. 2009. Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of Applied Research in Intellectual Disabilities* 22(1): 34-42.
- Tidy, C. 2013. *General Learning Disability*. www.patient. co.uk/doctor/general-learning-disability. [Final accessed 11 January 2015].
- Walsh, C.E., Mulder, E. & Tudor, M.E. 2013. Predictors of parent stress in a sample of children with ASD: Pain, problem behaviour, and parental coping. *Research in Autism Spectrum Disorders* 7: 256-264.
- World Health Organization. 2011. World Report on Disability. Geneva, Switzerland.

Azriani Ab Rahman Department of Community Medicine, School of Medical Sciences, Universiti Sains Malaysia, Health Campus, 16150 Kubang Kerian, Kelantan, Malaysia

Normah Che Din Health Psychology Programme, School of Healthcare Sciences, Faculty of Health Sciences, Universiti Kebangsaan Malaysia, Jalan Raja Muda Abdul Aziz, 50300 Kuala Lumpur, Malaysia