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

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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

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.
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
The socio-demographic information, (28/07/2016   09:38:22 IBM) consisted of socio-demographic characteristics included age, relationship to children, and disability related variables of the child. Socio-demographic characteristics of the caregivers and their background of children and caregivers, disability related variables and the Perceived Stress Scale 10 items (PSS-10) were distributed to the eligible caregivers. A signed form confirming informed consent was obtained from caregivers who agreed to participate. The background Information sheet consists of socio-demographic characteristics of the caregivers and their children, and disability related variables of the child. Socio-demographic 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, \( \alpha = 0.86 \).

### 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 authorities of the 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 a 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 socio-demographic characteristics of the caregivers and their children, and disability related variables of the child. Socio-demographic 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 (IQR = 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 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 2. Characteristics of the children with learning disabilities \((n = 40)\)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Mean (SD)</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years old)</td>
<td>10.61 (5.60)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Boy</td>
<td>23 (57.5)</td>
<td></td>
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<tr>
<td>Girl</td>
<td>17 (42.5)</td>
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<tr>
<td>Reported medical/health problems</td>
<td></td>
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<tr>
<td>No</td>
<td>23 (57.5)</td>
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<tr>
<td>Yes</td>
<td>17 (42.5)</td>
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<tr>
<td>Time since diagnosis (duration of disability) (years)</td>
<td>8.76 (5.11)</td>
<td></td>
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<tr>
<td>Care dependency</td>
<td>37.23 (14.89)</td>
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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)

*aScale 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 \((n = 40)\)

<table>
<thead>
<tr>
<th>Items</th>
<th>Mean (SD)</th>
<th>n (%)</th>
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<tbody>
<tr>
<td>In the last month, how often have you been upset because of something that happened unexpectedly?</td>
<td>1.93 (0.73)</td>
<td>3 (7.5) 2 (5.0) 31 (77.5) 3 (7.5) 1 (2.5)</td>
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<tr>
<td>In the last month, how often have you felt that you were unable to control the important things in your life?</td>
<td>1.45 (0.96)</td>
<td>9 (22.5) 8 (20.0) 19 (47.5) 4 (10.0) 0 (0.0)</td>
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<tr>
<td>In the last month, how often have you felt nervous and “stressed”?</td>
<td>1.45 (0.96)</td>
<td>10 (25.0) 5 (12.5) 22 (55.0) 3 (7.5) 0 (0.0)</td>
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<tr>
<td>In the last month, how often have you felt confident about your ability to handle your personal problems?</td>
<td>1.58 (0.96)</td>
<td>3 (7.5) 1 (2.5) 15 (37.5) 18 (45.0) 3 (7.5)</td>
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<tr>
<td>In the last month, how often have you felt that things were going your way?</td>
<td>1.95 (0.85)</td>
<td>3 (7.5) 3 (7.5) 24 (60.0) 9 (22.5) 1 (2.5)</td>
</tr>
<tr>
<td>In the last month, how often have you felt that you could not cope with all the things that you had to do?</td>
<td>1.40 (1.01)</td>
<td>11 (27.5) 6 (15.0) 19 (47.5) 4 (10.0) 0 (0.0)</td>
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<tr>
<td>In the last month, how often have you been able to control irritations in your life?</td>
<td>2.08 (1.02)</td>
<td>5 (12.5) 4 (10.0) 23 (57.5) 5 (12.5) 3 (7.5)</td>
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<tr>
<td>In the last month, how often have you been angered because of things that were outside of your control?</td>
<td>1.70 (0.85)</td>
<td>2 (5.0) 3 (7.5) 17 (42.5) 17 (42.5) 1 (2.5)</td>
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<td></td>
<td>1.85 (1.05)</td>
<td>5 (12.5) 8 (20.0) 17 (42.5) 8 (20.0) 2 (5.0)</td>
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</table>

*Continued*
In the last month, how often you felt difficulties were piling up so high that you could not overcome them?

10. Dalam tempoh sebulan ini, berapa kerap anda berasa kesusahan yang melampau sehingga anda tidak dapat mengatasinya?

In the last month, how often you felt difficulties were piling up so high that you could not overcome them?

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In the last month, how often you felt difficulties were piling up so high that you could not overcome them?
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.

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