

## ORIGINAL ARTICLE

## OFFICIAL JOURNAL

MJPC Vol. 29 (3) December 2023



## THE RELATIONSHIP BETWEEN COPING STRATEGIES AND PARENTING STRESS IN CHILDHOOD EPILEPSY

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### Abstract

**Background:** Epilepsy is a common childhood disease that can lead to high stress levels in parents, subsequently affecting family dynamics. The coping strategies practised by parents often play a major role in determining the level of parenting stress. **Objective:** This study aimed to identify the proportion of parents with parenting stress among those who have children with epilepsy, to compare the level of stress in different domains (parent, child, and parent-child interaction) as well as to examine the relationship between parenting stress and parental coping strategies. **Methods:** In this cross-sectional study, a total of 61 parents of children with epilepsy aged between 2 to 12 years old were recruited from the *Pusat Perubatan Universiti Kebangsaan Malaysia* (PPUKM) paediatric clinic over eight months. Validated questionnaires were used to determine the parenting stress level and coping strategies. **Results:** The proportion of parents with high stress scores (13.1%) was lower in this study compared to previous studies, except for non-Malay parents. Among the three domains, 29.5% of parents reported a high stress level under Parent-Child Dysfunctional Interaction (P-CDI). A negative correlation was observed between active coping and total parenting stress scores (TPSS) ( $r = -0.323$ ,  $p = 0.011$ ). In contrast, there was a positive correlation between self-blame coping and TPSS ( $r = 0.315$ ,  $p = 0.014$ ). **Conclusion:** Parents of children with epilepsy mostly reported low TPSS, except for non-Malays. Parents are encouraged to practise more active coping and less self-blame in managing children with newly diagnosed epilepsy.

**Keywords:** Parenting stress, Coping strategies, Epilepsy, Total Parenting Stress Score  
**DOI:** 10.51407/mjpc.v29i3.238

**Received:** 23 November 2022; **Accepted revised manuscript:** 17 August 2023; **Published online:** 26 December 2023

### Introduction

Clinically, epilepsy is diagnosed when an individual experiences two unprovoked seizures more than 24 hours apart. Seizures occur when the electrical signals that deliver messages between brain cells are disrupted. Childhood epilepsy is a chronic illness that can cause adverse effects on physical, mental, and social health. Furthermore, when the wellbeing of a child is affected, the parent-child relationship can be challenging and it can result in dysfunctional family dynamics [1].

Parenting stress is commonly experienced by many parents in their years of raising a child. While it is common, excessive stress can be detrimental to family dynamics. Parents with children who have chronic illnesses tend to experience a higher level of parenting stress compared to parents with normal healthy children [1-3]. In a study by Wirrell EC et al. [4], parenting stress was reported to be higher among those with epileptic children due to the associated behavioural, mood, and sleep disorders that can cast an impact on the parent-child relationship [4]. In a local study by Syed Abdullah et al. [5], the mean total

parental stress in parents of children with epilepsy was higher than in parents of children with acute leukaemia [2] and spina bifida [6] and high parenting stress among those with epilepsy children was associated with lower socioeconomic groups, those who had experienced recent life events, and those whose children had significant behavioural problems [5]. Another recent study also highlighted that emotional and behavioural symptom in children with epilepsy had a significant impact on parenting stress levels [7]. Hence, apart from treating the children's medical condition, attention should be given to the parents and caregivers as well to safeguard their mental and psychological health.

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In the literature, there are various predisposing factors of parenting stress. In an earlier study by Ong LC et al. [1], Chinese mothers who have children with cerebral palsy were found to have a higher risk of parenting stress compared to Malay and Indian mothers [1]. When comparing both parents, most studies reported a higher risk of parenting stress among mothers than fathers [1,4]. This can be attributed to the fact that mothers often play a more pivotal role in caregiving for unwell children. Some working mothers also need to juggle stress at work at the same time. It was also found that mothers often feel overburdened and poorly supported in caring for a child with epilepsy [4]. The same study reported that mothers lack emotional support from their spouses, besides being socially isolated from peers due to the demand of caregiving, subsequently leading to restricted freedom and poor health status [4].

Coping strategies play a fundamental role in overcoming stress. They refer to specific behavioural or psychological efforts that are used to master, tolerate, reduce, or minimise stressful events. Previous studies have shown the effects of problem-solving and emotion-focused strategies in overcoming stressful events [8]. Mohamed et al. [3] reported that fathers who practised task-oriented coping scored lower on the Total Parenting Stress Score (TPSS), a measure of the different types of parenting stress. In addition, Mohamed et al. [3] found that emotion-focused coping was significantly associated with higher parenting stress while task-oriented coping was associated with lower parenting stress. Avoidant or maladaptive coping strategies were also found to be associated with a higher level of parenting stress [9]. This study aimed to determine the proportion of parents of children with epilepsy with high levels of parenting stress, to compare the level of stress in different domains (parent, child, and parent-child interaction), as well as to examine the relationship between parenting stress and coping strategies.

### Materials and methods

This cross-sectional study was conducted at the *Hospital Pakar Kanak-Kanak* in *Pusat Perubatan University Kebangsaan Malaysia* (PPUKM) from December 2021 to August 2022. Parents of children aged between 2 and 12 years who fulfilled the inclusion criteria were selected and informed consent was obtained. The inclusion criteria were parents of children aged between 2-12 years old with a diagnosis of epilepsy for more than a year. Children with comorbidities (chronic illnesses, neurodevelopmental disorders, or behavioural disorders) and parents who are unable to read and understand Bahasa Malaysia were excluded. Convenience sampling was used. Medical records of patients were reviewed and potential parents were

recruited by the primary investigator with the help of staff nurses and doctors. Only one parent from each family was selected to answer a set of questionnaires. Ethical approval was obtained from the Medical Research and Ethics Committee, Faculty of Medicine, Universiti Kebangsaan Malaysia (FF-2021-498).

The questionnaires comprised sociodemographic data, Parental Stress Index Short Form 4<sup>th</sup> edition (PSI/SF), and Brief Coping Orientation to Problems Experienced (COPE). Validated versions of the Malay PSI/SF and Brief COPE were used after obtaining the permission of the authors. The PSI/SF consists of 36 items under three domains, i.e. 'parent distress', 'parent-child dysfunctional interaction (P-CDI)', and 'difficult child'. Each item is scored on a five-point Likert scale to determine the degree to which parents find each item to be a problem in their daily lives. The Total Parenting Score (TPSS) is determined by adding the scores from all three domains. In our study, a high TPSS is defined as scores above the 85<sup>th</sup> percentile. As for Brief COPE, it consists of two items for each of the 14 dimensions (self-distraction, active coping, denial, substance abuse, emotional support, instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame). All the 28 items are rated by a four-point Likert scale. There is no overall score and the score of each dimension shows how often a parent uses the coping strategy.

Statistical analysis was performed using IBM SPSS statistics version 27. Sociodemographic data were reported in frequency for categorical data and mean for continuous data. The different levels of stress under the three domains were presented as frequency and percentage. The group differences were analysed using Fisher exact test for categorical data and independent t-test for continuous data. Bivariate correlation was performed to determine the relationship between parental coping strategies and parenting stress levels.

### Results

A total of 107 parents of children with epilepsy fulfilled the inclusion criteria based on the medical records. However, 41 of them did not turn up for their routine clinic appointment and five declined to participate. A total of 61 parents of children with epilepsy participated in the study, including 38 (62.3%) mothers and 23 (37.7%) fathers. The mean age of the parents was  $39.3 \pm 4.9$  years. The majority of participants were Malays (67.2%). Most of them were employed (60.5% of the mothers and all of the fathers). The mean age of the children was  $8 \pm 2.8$  years. There were slightly more boys (57.4%). Most of them had severe epilepsy (77%) and 32.8% reported a history of cerebral palsy. Table 1 summarises the sociodemographic characteristics of the participants.

Table 1. Background characteristics of participants (n = 61).

<b>Characteristics</b>	<b>Mean (SD)</b>	<b>N (%)</b>
<b>Child</b>		
Age (years)	8.09 (2.8)	-
Duration of diagnosis (years)	5.24 (3.2)	-
<u>Seizure type</u>		
Severe	-	47 (77)
Non-severe	-	14 (23)
Cerebral palsy	-	20 (32.8)
No cerebral palsy	-	41 (67.2)
<b>Parents</b>		
Age (years)	39.3 (4.9)	-
<u>Relationship</u>		
Mother	-	38 (62.3)
Father	-	23 (37.7)
<u>Ethnicity</u>		
Malay	-	41 (67.2)
Non-Malay	-	20 (32.8)
<u>Number of children</u>		
0 - 2	-	26 (42.6)
3 and more	-	36 (57.4)
<u>Education level</u>		
Pre-University	-	36 (59)
University	-	25 (41)
<u>Income</u>		
Low	-	24 (39.3)
Middle	-	30 (49.2)
High	-	7 (11.5)
<u>Primary caregiver</u>		
No	-	28 (45.9)
Yes	-	33 (54.1)
Father as primary caregiver	-	7 (30.4)
Mother as primary caregiver	-	26 (68.4)
<u>Marital status</u>		
Married	-	60 (98.4)
Widowed	-	1 (1.6)
<u>Employment</u>		
Unemployed	-	15 (24.6)
Employed	-	46 (75.4)
Working Mother	-	23 (60.5)
Working Father	-	23 (100)

Figure 1 illustrates the parenting stress level based on TPSS from the PSI-SF. In this study, four parents reported a high level of stress (n = 4, 6.6%) and a clinically significant level of stress (n = 4, 6.6%) respectively. However, most parents (n = 53, 86.9%)

reported a normal level of stress. Across the three domains of PSI, parents with clinically significant levels of stress reported a higher level of stress under the domain of P-CDI (n = 13, 21.3%).

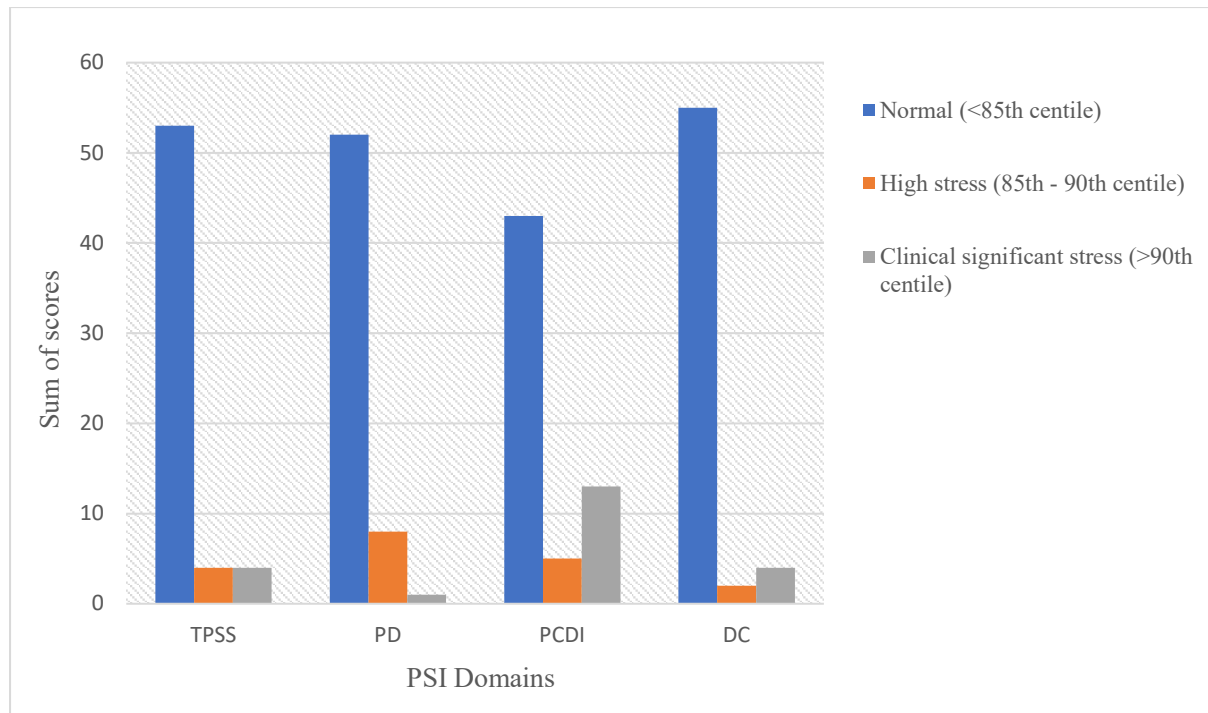


Figure 1. Parenting stress level according to Parenting Stress Index (PSI)<sup>®</sup>

Table 2 shows the mean parenting stress scores across the three domains. The mean TPSS was 84.5 ±

19.2 whereas the score range and mean scores of the three domains did not differ much.

Table 2. Distribution of parenting stress scores.

Subscales	Score Range	Mean ± SD
Total Parenting Stress Index (PSI)	40-125	84.5 (19.2)
Parental Distress (PD)	13-48	27.4 (8.4)
Parent-Child Dysfunctional Interaction (P-CDI)	13-45	28.6 (7.3)
Difficult Child (DC)	13-50	28.5 (7.0)

PSI: Parenting Stress Index

PD: Parent Distress

P-CDI: Parent-Child Dysfunctional Interaction

DC: Difficult Child

\*p-value <0.05

Table 3. Background characteristics according to the level of stress (n = 61).

Characteristics	Normal stress <85 <sup>th</sup> centile n = 53	High stress >85 <sup>th</sup> centile n = 8	P Value
Age of Children, mean (SD)	7.9 (2.76)	9.4 (2.55)	0.162 <sup>†</sup>
Relationship			
Mother	31 (81.6)	7 (18.4)	0.239*
Father	22 (95.7)	1 (4.3)	
Age of Parents, mean (SD)	39.1 (4.79)	40.5 (6.32)	0.456 <sup>†</sup>
Ethnicity			
Malay	39 (95.1)	2 (4.9)	0.012*
Non-Malay	14 (70)	6 (30)	
Number of Siblings			
0-2	21 (80.8)	5 (19.2)	0.268*
3-6	32 (91.4)	3 (8.6)	
Occupation			
Unemployed	11 (73.3)	4 (26.7)	0.093*
Employed	42 (91.3)	4 (8.7)	
Epilepsy Severity			
Non-Severe	11 (78.6)	3 (21.4)	0.369*
Severe	42 (89.3)	5 (10.6)	
Duration of Diagnosis, mean (SD)	5.1 (3.24)	6.5 (2.87)	0.239 <sup>†</sup>
Cerebral Palsy			
No	36 (87.8)	5 (12.2)	1.000*
Yes	17 (85)	3 (15)	
Caregiver			
Primary Caregiver	29 (87.9)	4 (12.1)	1.000*
Not Primary Caregiver	24 (85.7)	4 (14.3)	
Education Level			
Pre-University	30 (83.3)	6 (16.7)	0.453*
University	23 (92)	2 (8)	

\* Fisher's Exact Test

† Independent t-Test

Table 3 shows a lack of significant association between parental characteristics of parents and stress level, except for ethnicity (p = 0.012). However, these results need to be interpreted with caution due to the low number of parents with high stress levels.

Figure 2 shows the mean score of coping strategies used by participants. Coping strategies that are used most often by parents were active coping (3.21) followed by religion (3.18), acceptance (3.16), positive reframing (3.15), and planning (3.04). The coping strategies that were least used included substance abuse (1.11), behaviour disengagement (1.45), denial (1.79), and self-blame (1.89).

Table 4 shows the relationship between the different coping strategies and parenting stress. From our analysis, a negative correlation was seen between the usage of active coping and TPSS. The correlation was clinically significant (r = -0.32, p = 0.011). In contrast, there was a positive correlation between the usage of

self-blame and TPSS (r = 0.31, p = 0.011). In other words, parents who practised active coping tend to have a lower TPSS while those who practised self-blame were more likely to have a higher TPSS.

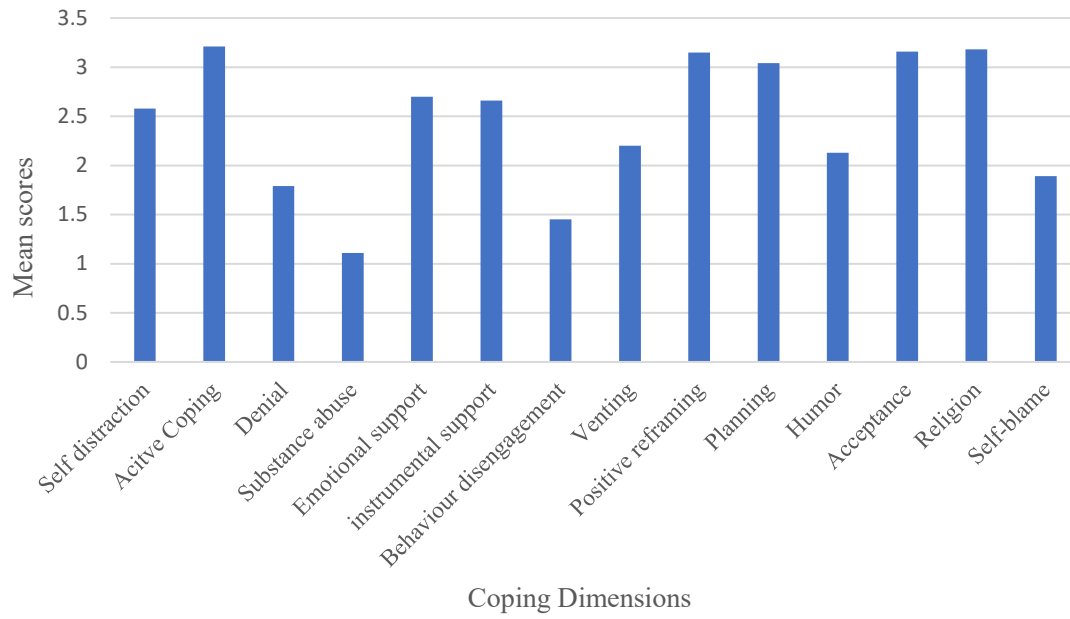


Figure 2. Mean scores of coping strategies used.

Table 4. Correlation between parental coping strategies and parenting stress.

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1 TPSS																	
2 PD	.82**																
3 P-CDI	.89**	.57**															
4 DC	.84**	.46**	.72**														
5 Self-destruction	0.15	0.25	0.07	0.06													
6 Active coping	-.32*	-.30*	-.34**	-.18	.30*												
7 Denial	0.09	0.21	-0.02	0.01	.26*	0.13											
8 Substance abuse	0.09	0.15	-0.02	0.09	0.06	0.12	.45**										
9 Emotional support	0.09	0.13	0.01	0.09	.41**	.33**	.30*	0.13									
10 Instrumental support	0.14	0.2	0.03	0.11	.38**	.35**	0.14	-0.07	.71**								
11 Behaviour disengagement	0.13	0.17	0.05	0.09	0.06	0	.38**	.58**	0.1	0.03							
12 Venting	0.14	0.17	0.08	0.1	.39**	.38**	.38**	0.2	.55**	.43**	.30*						
13 Positive reframing	-0.16	-0.16	-0.12	-0.13	0.24	.49**	0.12	-0.16	.35**	.40**	-0.15	0.14					
14 Planning	-0.23	-0.22	-0.21	-0.16	.28*	.76**	0.16	-0.01	.29*	.50**	0	.31*	.65**				
15 Humor	-0.01	0.11	-0.02	-0.13	.45**	.40**	.31*	0.23	.33**	.35**	0.24	.50**	.34**	.41**			
16 Acceptance	-0.2	-0.11	-0.17	-0.24	.26*	.72**	0.03	-0.15	.30*	.35**	-0.22	0.21	.64**	.66**	.41**		
17 Religion	-0.23	-.32*	-0.1	-0.15	0.13	.25*	0.15	-0.13	.25*	0.22	-0.2	0.08	.81**	.46**	0.23	.40**	
18 Self-blame	.31*	.41**	0.2	0.17	.26*	0.06	.72**	.41**	.47**	.28*	.37**	.44**	0.05	0.04	.35**	0.04	-0.03

\*Correlation is significant at 0.05 level

\*\*Correlation is significant at 0.01 level

## Discussion

Parents play a vital role in the caregiving and upbringing of their children. This is especially true for children with chronic conditions such as epilepsy. Parents have a significant role in helping the child to adapt to their condition, comply with their treatment, as well as helping the child to function in and outside their homes [10]. Such demands have led to a higher level of stress among parents of children with epilepsy [11]. In addition, studies have also shown that these parents have a lower quality of life [12]. Therefore, the inculcation of appropriate coping strategies is necessary to improve parental-child interaction and relationships in order to reduce parenting stress and improve their quality of life.

In this study, the proportion of parents with high TPSS was rather low at 13%, with a mean TPSS value of 84.5. This was much lower than the mean TPSS of 97.8 reported in a previous study by Syed Abdullah et al. [5]. The significant improvement in the stress level among parents of epilepsy children in the past 18 years can be partly due to the improved parental knowledge of epilepsy as a result of easily accessible information about epilepsy. Furthermore, the advent of information technology enables parents nowadays to seek information regarding their children's condition and to equip themselves with accurate knowledge. Additionally, the stress level could have been reduced following advancements in the management of epilepsy in recent years with the availability of new epileptic therapies such as the ketogenic diet and surgical procedures. However, such comparison needs to be interpreted with caution as the diagnosis or type of epilepsy in the previous study may differ from our study. Moreover, this study was conducted during the COVID-19 pandemic, hence many parents could have missed the follow-up appointment. Therefore, there is a likelihood that some of the parents who defaulted might have been those with a high stress level, thus resulting in possible under-reporting of parents in the high stress group.

Next, in contrast to previous studies that reported no significant difference in stress levels among different ethnic groups [9], the non-Malay parents in this study had a higher level of stress. However, a larger study is needed to confirm this finding in view of the small sample size of total parents and parents with high levels of stress. In terms of the types of clinical conditions, previous studies reported that parents with an Autistic Spectrum Disorder (ASD) child have a high level of stress Lee et al. [13]. These parents also tend to score higher in the domain of difficult children as their child's behavioural problems are the main contributing factor to a high level of stress [13]. In our study, the lower level of stress may also be related to the exclusion of children with neurodevelopmental and behavioural disorders such as ASD and attention-deficit hyperactivity disorder (ADHD).

In comparison, parents in this study showed a higher level of stress in the P-CDI domain than the DC domain, likely due to the specific inclusion of epilepsy children with cerebral palsy. High scores in the P-CDI domain suggest that the parent-child bond either is threatened or has never been adequately established. Children with cerebral palsy may not be able to interact with parents in a similar way as a typically developing child would in terms of verbal and non-verbal interactions. In other words, the child may be perceived as not meeting their parents' expectations, and in turn, the parents do not reinforce their roles as a parent. In a study among Malaysian mothers with cerebral palsy, there were significantly higher mean scores on all subscales of the child domain and parent domain, with higher mean life stress scores than the controls [1].

Bringing up a child with disabilities is known to influence the parenting stress level. Parents with disabled children sometimes blame themselves for their child's disability, indirectly causing a higher level of parenting stress [14]. For instance, mothers sometimes attribute the child's epilepsy or disability to neglect or other problems arising during pregnancy and delivery. Furthermore, they may be reluctant to let their friends know about their child's condition because of a sense of shame, self-blame, or rejection [10]. As a result, this could affect the parental-child interaction as the parent's expectations of their child cannot be met. In our study, there was no significant difference between the level of stress experienced by mothers and fathers. However, previous studies reported a higher level of stress among mothers while fathers appeared to cope better with their stress [9]. The most possible explanation is that mothers are usually more involved in child-rearing while fathers work as the breadwinner for the family. Some studies also highlighted that a higher level of stress among mothers could be attributed to their dual role as primary caregivers at home [1, 15] besides working outside their homes. However, in this study, the level of stress was similar among parents who were the primary caregiver and those who were not. We postulated that the lower level of stress in our study population may be explained by a larger percentage of participants who were working parents and therefore, presumably spent less time with their children.

In view of the effect of parenting stress on the family, coping strategies play an important role in mitigating the level of parenting stress. Previous studies have shown a negative correlation between problem-focused coping and stress levels [16]. On the contrary, other studies reported that emotion-focused coping strategies and maladaptive coping strategies resulted in higher parenting stress [17]. In another recent study, parents with psychological distress reported more use of substance abuse, denial, and behavioural

disengagement [18]. In this study, the most commonly used coping strategy was active coping while the least used was substance abuse. We also found a negative correlation between active coping and level of stress and a positive correlation between self-blame and level of stress. Hence, this could explain the lower percentage of parents with high stress in this study compared to previous studies as more parents were practising active coping than self-blame. In addition, this shows that the current generation of parents actively look for solutions as part of problem-focused coping in the efforts to solve their problems and reduce their stress levels.

Last but not least, even though there was a higher percentage of severe epilepsy among the children in this study, the proportion of parents with a high stress level was only 10%. The high number of defaulters during the data collection period that coincided with the COVID-19 pandemic could have reduced the number of parents with high stress levels. However, even though the results showed that most parents were coping well, it is undeniable that interventions are still needed to assist these parents to have a better quality of life, especially those who reported a high level of stress. Based on our findings, we recommend that the at-risk parents be identified during clinic consultation so that they can be given the appropriate counselling on active coping to reduce their parenting stress. They should be provided with access to the right sources of information and reference materials. By encouraging them to join the parents' support group, they can share information and experience with other parents. More importantly, they should be reminded to enhance their interaction with their children by engaging them in fun family activities that can improve both the parental-child relationship and their expectations.

There are certain limitations to this study. Firstly, we did not explore the role of extended family members such as grandparents who can help the parents in looking after the child or performing household chores. Such family support can reduce the parental burden and lower stress levels. As many patients could not attend the follow-up during the COVID-19 pandemic, the number of study participants was rather limited. Studies with a larger sample size will provide better statistical power. Furthermore, this study focused only on children with epilepsy and cerebral palsy. Different challenges may be present for children with other behavioural problems.

In conclusion, our study reported a lower level of parenting stress compared to previous studies, likely due to the exclusion of children with behavioural problems. A better coping mechanism among parents could also be the reason behind the lower level of stress.

## Acknowledgements

The authors express their gratitude to Dr. Farah Inaz and M. Nasir Yusof for their support and contributions to this study.

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