Original Article

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The Caregivers' Knowledge on Epilepsy and its Relationship with Stress Levels

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ABSTRACT

Background: Eighty percent of 50 million people who live in economically underdeveloped and developing countries tend to have epilepsy, and more than 50 million people worldwide suffer from this condition. **Objective:** To determine the levels of knowledge about epilepsy among carers and the relationship this has with their stress levels. **Methods:** A cross-sectional study design was employed using probability systematic sampling. All the data obtained were analysed using the Statistical Package for Social Sciences (SPSS) version 22. **Results:** In total, 308 respondents participated in this study. A significant association was found between carers' knowledge levels and stress levels. A significant association was identified between educational level, monthly income, and level of knowledge. However, the results reveal no significant association between carer knowledge and the socio-demographic characteristics of age, gender, and religion. Similarly, no significant association was identified between socio-demographic characteristics and stress levels. **Conclusion:** This study revealed that most carers who have family members with epilepsy experience moderate levels of stress, even though they have high levels of knowledge. Therefore, stress levels among carers can be reduced by implementing health education related to stress management. Therefore, good knowledge on epilepsy and good social support will reduce stress levels among carers.

Keywords: Caregiver; Epilepsy; Knowledge; Stress

INTRODUCTION

Some carers may not have extensive knowledge of their epileptic family member's condition. A local study by Neni *et al*. (2010) claimed that the considerable epilepsy treatment gaps were probably caused by low parental levels of awareness and knowledge of epilepsy and how it affects the family member. The academic achievements of school-age epileptic family members may be affected. In Malaysian, the most dominant cognitive problems experienced by children with epilepsy is memory issue (Letchemanan & Low, 2024). Oyegbile-Chidi *et al*. (2023) stated that children with epilepsy have consistently been found to exhibit lower levels of academic achievement than their siblings and healthy peers. This may be one reason for stress among carers, who might fear that their children will have problems with their studies.

Furthermore, epilepsy in a family member may also have financial effects. Jennum *et al.* (2011) emphasised that patients with epilepsy incurred significantly higher costs, such as those related to hospitalisation, outpatient visits, drugs, as well as visits to general practitioners and practicing specialists in the public and private sectors. Carers need to spend more money on a family member with epilepsy than on other members, which sometimes increases carers' stress levels. Besides, a person with epilepsy may encounter problems performing physical activities in their daily life, and they sometimes can't perform their usual daily activities after an epilepsy attack. Lin, Mula, and Hermann (2012) claimed that patients with epilepsy and psychiatric comorbidities had more limitations and disabilities than could be attributed to the

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epilepsy itself. During an attack, their physical activities are performed and their needs are met by the carer, such as when the latter maintains the patient's self-hygiene.

In addition, misconceptions about epilepsy may affect the stress levels among carers with an epileptic family member. In Malaysia, epilepsy is still a highly misunderstood illness, and patients are often avoided by the public (Wo *et al.*, 2018; Kuai, 2024). Thus, knowing the degree of epilepsy knowledge among carers is important in helping to overcome their high stress levels, while it is essential to enabling the provision of better care for family members with that chronic neurological disease. A limited number of studies are directly related to the topic of carers' knowledge of epilepsy and the relationship this has with their stress levels. Much research has been conducted that focusses specifically on parental awareness of their children's epilepsy. In other words, those studies have only measured levels of parental awareness in relation to epilepsy patients below 12 years old. Moreover, few epilepsy studies have been undertaken at Hospital Kuala Lumpur. An earlier study was carried out in Istanbul, Turkey, in 2016 (Ustuner, Cam & Bora Güneş, 2024). This study focused exclusively on the impact of epilepsy on preschool-aged children and their families. Findings indicated that as individuals grow older, the significant effects of their neurological condition on family stress levels and personal quality of life tend to decrease.

A recent study of awareness of knowledge of, and attitudes towards epilepsy among Malaysia show negative societal attitudes toward the condition (Kayar & Sahin, 2024). Another study by Neni *et al*. (2010) was conducted twelve years ago. Therefore, given the limited number of epilepsy studies that have been performed in urban areas, this study would be conducted in Selangor. The aims of this study were to determine carers' knowledge of epilepsy and the relationship this had with their stress levels.

Knowledge of Epilepsy

To provide better care for an epileptic family member, the caregiver needs good information resources. A previous study revealed that the families of epileptic children who had been taken to a neurology clinic were asked about their sources of accurate information related to their child's disease (Elliott & Shneker, 2008). Caregiver knowledge of epilepsy was found to affect epilepsy treatment compliance to some extent, especially in younger epileptic family members. Chen, Lee and Hie (2013) claimed that if a caregiver has a substantial amount of information and knowledge about epilepsy, this enhances their confidence in administering the necessary medicines and providing care during an epilepsy attack.

Epilepsy and Caregiver Stress Levels

Parents or caregivers with an epileptic family member may have a higher tendency to display stress and face increased burdens in their daily lives (Okiah *et al*., 2023; Yang *et al.*, 2023). Taking care of an epileptic family member is a challenging responsibility, and it may affect the daily routines of the other family members. In addition, some epilepsy patients may have social interaction problems with others in the community. This issue means that fewer parents of epileptic children are confident about allowing their children to participate in social activities, compared to parents who are confident about doing this (Gazibara *et al*., 2014). Thus, an epilepsy patient will be beside the carer most of the time, restricting the family member's time and activity (Akay *et al*., 2011; Othman *et al*., 2023).

Modi (2009) stated that both parents and children experience significant stress once it is well known that the child has been diagnosed with epilepsy. On the other hand, it is hard for many caregivers to accept the reality that their family member has a chronic neurological disease. The caregiver of a child with a chronic condition must manage the daily care burden related to the illness and the constantly changing demands of the condition. According to studies, parenting stress is actually higher among 45% to 65% of parents whose children have intractable epilepsy (Modi, 2009). Such parents may experience pressure for a variety of reasons.

A previous study by Cousino and Hazen (2013) claimed that epilepsy patients' potentially shortened life expectancy, the medical risks and complications, the child's diagnosis, and the need to care for the child at home are the reasons why parents experience more stress. Caregivers need to care more for the epileptic family member to prevent a sudden attack of epilepsy because epilepsy patients are sometimes highly sensitive to the external environment. Financial problems when caring for a family member with epilepsy can be classified as a major issue. A caregiver might lose earnings or be unable to take up employment due to their caring duties (Thompson *et al.*, 2014). In addition, some caregivers have to support the needs of the other family members. The consequence of these issues may be a higher level of stress among carers.

Symptomatic seizures are caused by exposure to injury, infection, or insufficient care (Ibinga *et al.*, 2015). Epilepsy patients might display altered behaviour after they have a sudden epilepsy attack. The prevalence of behavioural disorders in children with epilepsy varies from 20% to 60% in developed countries. Some caregivers are excessively caring towards their epileptic family member. Saada, Wang, and Bautista (2015) claimed that caregivers have a high tendency to become overly protective. Unfortunately, this can lead the epileptic family member to develop depression as they compare the way they are treated by the caregiver to the way others are treated. Caring for epilepsy is emotionally demanding, and carers are at greater risk of stress and depression (Elliott & Shneker, 2008).

METHODOLOGY

In this study, the sampling method used was probability systematic sampling. A name list of caregivers with an epileptic family member in Selangor was collected from the Malaysian Epilepsy Association's official Facebook page. A total of 1160 caregivers were named and listed. After that, every third name on the list was chosen as a potential respondent and contacted through direct messaging. If they agreed with the informed consent form and fulfilled the inclusion criteria, they were given an online questionnaire and recruited as respondents. The total number of respondents was 308. Vicars and McKenna (2015) state that the researcher has a responsibility to protect study participants from damage and from stressful situations. Given that participants in the study are humans, it is vital to comprehend research ethics before beginning any investigation.

The Awareness Knowledge Attitude Questionnaire (AKA Questionnaire) and a Perceived Stress Scale (PSS) questionnaire were used as the tools in this study. The Statistical Package for Social Sciences (SPSS) version 22 was used to analyse the data.

Ethical Consideration

The present study received ethical approval and permission to conduct the study from Jawatankuasa Etika Untuk Penyelidikan Manusia (JKEUPM), Malaysia and Universiti Putra Malaysia, Malaysia with reference number UPM/TNCPI/RMC/1.4.18.2(JKEUPM) on 13th May 2019.

RESULTS

Participants' socio-demographic data

In terms of monthly income, 5.5% of the respondents were of low-income status, earning less than RM 1,000 per month. A further 9.1% had monthly incomes of between RM 1,001 and RM 2,000. Next, 26% of the respondents had moderate monthly incomes of RM 2,001 to RM 3,000, 16.6% had monthly incomes of RM 4,001 to RM 5,000 and 14.3% had high monthly incomes of more than RM 5,000.

Levels of knowledge about epilepsy among caregivers with an epileptic family member

In terms of knowledge, 15.3% of respondents had poor knowledge, 20.5% had moderate knowledge, and 0.3% of respondents had very low knowledge. However, 15.6% of respondents had a very high level of expertise, compared to 48.4% of all respondents who had a high degree of knowledge.

Knowledge level scores among caregivers with an epileptic family member

A 92.2% of respondents were aware that epilepsy is not an infectious condition, while 59.4% of respondents were aware of the causes of epilepsy. However, only 41.6% of the participants were aware that a family member may have epilepsy. Furthermore, 82.5% of respondents did not believe that an evil spirit could cause epilepsy, despite the majority of respondents being aware that epilepsy is not a mental illness. Moreover, 56.2% of the participants acknowledged that epilepsy could result in death. Next, just 34.7% of participants were aware that there is no known cure for epilepsy. Furthermore, 47.4% of all respondents were proficient in providing emergency care in the event of an abrupt epileptic seizure.

Levels of stress among caregivers with an epileptic family member

In total, 10.1% of the respondents had low levels of stress. Most (84.4%) exhibited moderate levels of stress. A minimal percentage of the respondents (5.5%) had high levels of stress.

Lastly, this study found that respondents with monthly incomes of RM 3,001 to RM 4,000 had the highest percentage of moderate stress levels, 23.7%. There was no significant association between monthly income and knowledge level, with a *p*-value of more than 0.005 (*p*=0.063) (refer to Table 1).

Table 1: Relationship Between Socio Demographic Data and Level of Stress

Variables	**Level of Stress**			X^2(*df*)	***p*- value**
	0-13	14-26	27-40		
	Low stress *n* (%)	Moderate stress *n* (%)	High Stress *n* (%)		
Age				8.87(6)	0.181
21-30	4 (1.2)	51 (16.5)	7 (2.2)		
31-40	15 (4.8)	119 (38.6)	4 (1.2)		
41-50	10 (3.2)	65 (21.1)	3 (0.9)		
Above 50	2 (0.6)	25 (8.1)	3 (0.9)		
Gender				1.90(2)	0.386
Male	10 (3.2)	88 (28.5)	3 (0.9)		
Female	21 (6.8)	172 (55.8)	14 (4.5)		
Religion				11.10(8)	0.196
Islam	22 (7.1)	170 (34.7)	9 (2.9)		
Christian	3 (0.9)	32 (10.3)	6 (1.9)		
Buddha	1 (0.3)	31 (10.0)	1 (0.3)		
Hindu	4 (1.2)	20 (6.49)	1 (0.3)		
Others	1 (0.3)	7 (2.2)	-		
Marital Status				2.25(4)	0.688
Single	3 (0.9)	29 (9.4)	2 (0.6)		
Married	24 (7.7)	206 (66.8)	15 (4.8)		
Divorced	4 (1.2)	25 (8.1)	-		
Educational Level				5.65(8)	0.686
Secondary school	4 (1.2)	37 (12.0)	2 (0.6)		
Diploma/ STPM	11 (3.5)	101 (32.7)	10 (3.2)		
Degree	12 (3.1)	95 (30.8)	5 (1.6)		
Master	3 (0.9)	25 (8.1)	-		
Ph.D	1 (0.3)	2 (0.6)	-		
Monthly Income				17.53(10)	0.063
< RM 1000	1 (0.3)	13 (4.2)	3 (0.9)		
RM 1001-RM 2000	2(0.6)	22 (7.1)	4 (1.2)		
RM 2001-RM 3000	4 (1.2)	71 (23.0)	5 (1.6)		
RM 3001-RM 4000	11 (3.5)	73 (23.7)	4 (1.2)		
RM 4001-RM 5000	8 (2.5)	43 (13.9)	-		
> RM 5000	5 (1.6)	38 (12.3)	1 (0.3)		

**Correlation is significant at p-value < 0.05*

Socio-demographic characteristics and stress levels among caregivers with family members with epilepsy

Most respondents aged between 31 and 40 years old displayed moderate levels of stress, amounting to

38.5%. No significant association was found between religion and knowledge level, with a *p*-value of more than 0.005 (*p*=0.181). In terms of gender, the table shows that at 55.8%, more female than male respondents had moderate stress levels. No significant association was identified between gender and knowledge level, with a *p*-value of more than 0.005 (*p*=0.386).

Turning to religion as a factor, more Muslim respondents (34.7%) had moderate levels of stress compared to those of other religions. No significant association was found between religion and knowledge level, with a p-value of more than 0.005 (*p*=0.196).

Moreover, at 66.8%, married respondents were the group with the highest percentage of moderate stress, compared to those who were single or divorced. There was no significant association between marital status and knowledge level, with a *p*-value of more than 0.005 (*p*=0.688).

Furthermore, in relation to education, more respondents who had been educated to diploma or STPM level (32.7%) had moderate stress levels, compared to those of other educational levels. There was no significant association between educational level and knowledge level, with a *p*-value of more than 0.005 (*p*=0.686).

The association between caregivers' levels of knowledge about epilepsy and their stress levels

The normality test for both continuous variables was based on the values of Skewness (0.233 and 1.139), while the values of Kurtosis were 0.358 and 0.277. However, the Skewness values exceeded the range of -1 to 1. The data were considered to be not normally distributed. In addition, the Shapiro-Wilk had a *p*-value of < 0.05 (*p*=0.038). According to Shapiro-Wilk, this reflects data that are not normally distributed. Therefore, Spearman's correlation test was used to determine the association between caregiver levels of knowledge about epilepsy and the relationship this had with their stress levels.

Based on the data analysis, Spearman's correlation test indicated a significant association between caregivers' levels of knowledge and their stress level, with a *p*-value of 0.006 (*p*<0.05).

On the other hand, the r - value was - 0.156, placing it in the range of (- 0.3) to (- 0.1). This was interpreted as a negative, weak correlation between the caregivers' levels of knowledge about epilepsy and their stress level. Thus, a higher level of caregiver knowledge about epilepsy was connected to a reduced level of stress (refer to Table 2)

Table 2: The Association for Caregiver Level of Knowledge on Epilepsy and its Relationship with the Stress Level

Variables	**Level of Stress**	
	p-value	*r*-value
Level of Knowledge	0.006	-0.156

**Correlation is significant at p-value < 0.05*

DISCUSSION

Levels of knowledge about epilepsy among caregivers with an epileptic family member

As can be observed in the findings of this study, 48.4% of the respondents were rated as having high levels of knowledge, and 15.6% had very high levels of knowledge. These results are similar to those of a previous study by Gazibara *et al*. (2014), who found that slightly more than half of all the respondents in their survey (53.1%) considered themselves highly knowledgeable about epilepsy. Therefore, they claimed a high level of knowledge regarding epilepsy. In their study findings, almost 99.5% of the respondents knew that epilepsy is not an infectious disease. The rate resembled that of this study, in which 91.6% of the respondents correctly answered the question about whether epilepsy is an infectious disease. However, another study by Ezeala-Adikaibe *et al*. (2014) revealed that about 76.8% of the respondents made an incorrect attribution in relation to the cause of epilepsy (saying that epilepsy was infectious).

Meanwhile, the percentage of respondents who didn't know how to perform emergency help for an epilepsy attack was 54.45%. Another study by Cabral *et al.* (2014) found that 45.7%, almost half of the respondents, lacked first aid knowledge. This was because they were too frightened, as well as because they feared self-injury or infectious contact. The finding was differed from study in China, it reported Chinese families have a positive attitude toward the management of out-hospital acute seizure but lack of practice and related knowledge (Cui *et al*., 2023).

However, a study conducted in Kuala Terengganu by Neni *et al*. (2010) found that all their respondents had only moderate levels of knowledge. This was possibly caused by a lack of awareness regarding epilepsy among caregivers or family members. This lack of awareness was found to affect the quality of caregiving because a high level of knowledge led to parents performing their role well. Overall, this study revealed that most caregivers with an epileptic family member in Selangor had high or very high knowledge levels regarding the condition.

Stress levels among caregivers with an epileptic family member

Having a family member with severe epilepsy presents many unique challenges that a caregiver must consider when providing care. Although most adult patients with epilepsy live and manage their condition on their own, they may remain dependent on family members or partners for medical care. This explains why caring for epileptic family members is emotionally demanding and caregivers are at a greater risk of stress and depression (Elliott & Shneker, 2008; Viny *et al*., 2023; Othman *et al*., 2023).

According to the current study, 84.4% of caregivers with an epileptic family member had moderate stress levels. Furthermore, a previous study found that the parents of children considered clinically depressed due to epilepsy reported significantly higher parental distress scores ($p< 0.05$) (Cushner-Weinstein *et al*., 2008). In addition, higher levels of depression and stress ($p< 0.006$) were identified in caregivers who perceive that an epileptic member of their family has other health problems, as the results from a similar study show (Wei *et al*., 2022).

Caregiver distress can be caused by several factors, for example, fatigue, low energy levels, confusion, poor knowledge, low self-esteem, worrying about epilepsy-related complications, and a lack of mental clarity related to the disease. However, the results from a study by Saburi (2011) showed that 71% of the respondents were stressed. This was because of their sadness and fear that their epileptic family member would live with them forever due to concerns about how the disease would affect the patient during their absence.

On the other hand, this study revealed that 41.6% of the respondents had often experienced difficulties in adapting to the prolonged problems related to care, and many thought that they would not overcome this feeling. This may have been due to the burden and responsibility of caring for a family member with complex needs (Thompson *et al*., 2014). In total, 79% of the respondents had often felt that they had suffered an upsetting situation in the previous month. This was likely due to their frustration about the patient's health condition and fear of epilepsy attacks (Rodenburg *et al*., 2011).

The association between caregiver's levels of knowledge about epilepsy and their stress levels

Caring for a neurological condition at home can cause family members significant levels of stress, which can be detrimental to their own physical and psychological health. This study revealed a significant association between the caregivers' level of knowledge and their level of stress, with a p-value < 0.01 ($p = 0.006$). A similar result was identified in the study by Dravet (2011), who found a significant correlation between behavioural knowledge and caregiving stress. More knowledgeable carers felt more competent and confident as caregivers to an epileptic family member.

Graham, Ballard and Sham (1997) found nearly identical results: carers with higher knowledge levels had significantly lower rates of stress and depression ($p = 0.034$). A knowledgeable caregiver tends to think rationally before making a decision on behalf of a family member with a medical condition.

Makhado and Davhana-Maselesele (2016) revealed a significant association between carers' total knowledge level and their level of stress and emotional exhaustion ($p = 0.001$). Adequate knowledge plays a vital role in caring for a family member with a medical condition because carers are the individuals who are always with the sick family member. Even the basic duties and responsibilities of carers need knowledge, such as maintaining patient hygiene and providing emergency help during an attack of the disease. Carers tend to feel unsatisfied if they cannot provide the highest-quality care. The impact of this is that they tend to suffer from stress and emotional problems.

Nurses are essential in identifying and managing caregiver stress, which can have a major effect on the standard of care given to patients with epilepsy. By conducting thorough evaluations, nurses are able to spot caregivers who could be under a lot of stress and offer focused interventions to help them. This can involve facilitating access to resources like counseling and support groups, educating people about stress management strategies, and providing emotional support. Nurses can assist guarantee that caregivers are better prepared to offer appropriate care and support to people with epilepsy, hence enhancing their overall quality of life, by addressing caregiver stress.

The findings indicate that 48.4% of respondents had high levels of knowledge, and 15.6% had very high levels of knowledge about epilepsy. These results align with a previous study by Gazibara *et al*. (2014), which found that slightly more than half of the respondents (53.1%) considered themselves highly knowledgeable about epilepsy. Nurses play a crucial role in ensuring that caregivers possess the health literacy and information needed to provide appropriate care for patients with epilepsy. Educating people on epilepsy's causes, symptoms, available treatments, and management techniques is part of this. Additionally, nurses may help caregivers get connected to social support networks like support groups and local services, which can offer them much-needed emotional and practical support. Nurses can enable caregivers to effectively care for and assist people with epilepsy, thereby enhancing their general well-being and quality of life, by encouraging health literacy and social support.

CONCLUSION

Consequently, it is crucial that both the caregiver and the patient are thoroughly assessed in interventions aimed at alleviating caregiver burden in individuals with epilepsy, as this burden is influenced by a range of sociodemographic and psychosocial factors related to both the patient and the caregiver. Therefore, misconceptions and misinformation should be identified and corrected as part of optimal care and management. Moreover, increased awareness and educational programs are needed for future research to upgrade knowledge about epilepsy, which might reduce the stress levels among caregivers with an epileptic family member.

Recommendations

Nurses could make home visits to an epilepsy patient's house to assess the living environment and ensure that it will help to prevent injuries if the patient has a sudden epilepsy attack. In addition, nurses could form volunteer or family support groups within the community to provide emotional support to both the caregiver and the epileptic person. Within this program, they could share similar caring experiences with other family caregivers in addition to obtaining social support. This would subsequently help to improve caregivers' knowledge and reduce their stress. Furthermore, the authors suggest the need for studies that utilise more comprehensive techniques, such as a larger sample size and a broader study location. These could be used as sources from which to develop structured and comprehensive epilepsy educational programs. This is because it is necessary that caregivers with an epileptic family member receive continuous and repeated health education to prevent and reduce the negative effects of epilepsy.

The caregiver and the epilepsy patient could collaborate with other parties, such as government agencies and non-government organisations (NGOs). This would introduce them to the various forms of assistance related to epilepsy. Several epilepsy-related organisations operate in Malaysia. For example, an epilepsy patient or their caregiver can join the Persatuan Epilepsi Malaysia (Malaysian Society of Epilepsy). This society provides various types of support systems, such as Epilepsy Awareness Weeks, Walkathons, Family Days, Annual General Meetings and Medical Camps.

Through this type of society, epilepsy patients and caregivers can open their minds and express their problems and opinions. This is because the relevant NGOs are operated by medical professional volunteers and offer good networking with the community, the government and the private sector.

Conflict of Interest

The authors declare no conflict of interest with respect to the research, authorship, and publication of this article.

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REFERENCES

Akay, A. P., Kurul, S. H., Ozek, H., Cengizhan, S., Emiroglu, N., & Ellidokuz, H. (2011). Maternal reactions to a child with epilepsy: Depression, anxiety, parental attitudes and family functions. *Epilepsy Research, 95*(3), 213-220. https://doi.org/10.1016/j.eplepsyres.2011.03.020

Cabral, L., Duarte, J., Ferreira, M., & dos Santos, C. (2014). Anxiety, stress and depression in family caregivers of the mentally ill. *Atención Primaria, 46*, 176-179. https://doi.org/10.1016/S0212-6567(14)70087-3

Chen, C., Lee, D. S. H., & Hie, S. L. (2013). The impact of pharmacist's counseling on pediatric patients' caregiver's knowledge on epilepsy and its treatment in a tertiary hospital. *International Journal of Clinical Pharmacy, 35*, 829-834. https://doi.org/10.1007/s11096-013-9817-5

Cousino, M. K., & Hazen, R. A. (2013). Parenting stress among caregivers of children with chronic illness: a systematic review. *Journal of Pediatric Psychology, 38*(8), 809-828. https://doi.org/10.1093/jpepsy/jst049

Cui, C., Li, S., Chen, W., Zhou, H., & Zheng, X. (2023). Chinese families' knowledge, attitudes, and practices regarding seizure management for children with epilepsy: A mixed-methods study. *Frontiers in Public Health, 11*. https://doi.org/10.3389/fpubh.2023.1081720

Cushner-Weinstein, S., Dassoulas, K., Salpekar, J. A., Henderson, S. E., Pearl, P. L., Gaillard, W. D., & Weinstein, S. L. (2008). Parenting stress and childhood epilepsy: The impact of depression, learning, and seizure-related factors. *Epilepsy & Behavior, 13*(1), 109-114. https://doi.org/10.1016/j.yebeh.2008.03.010

Dravet, C. (2011). Dravet syndrome history. *Developmental Medicine & Child Neurology, 53*, 1-6. https://doi.org/10.1111/j.1469-8749.2011.03964.x

Elliott, J., & Shneker, B. (2008). Patient, caregiver, and health care practitioner knowledge of, beliefs about, and attitudes toward epilepsy. *Epilepsy & Behavior, 12*(4), 547-556. https://doi.org/10.1016/j.yebeh.2007.11.008

Ezeala-Adikaibe, B. A., Achor, J. U., Nwabueze, A. C., Agomoh, A. O., Chikani, M., Ekenze, O. S., ... & Orakwue, M. (2014). Knowledge, attitude and practice of epilepsy among community residents in Enugu, Southeast Nigeria. *Seizure, 23*(10), 882-888. https://doi.org/10.1016/j.seizure.2014.08.003

Gazibara, T., Nikolovski, J., Lakic, A., Pekmezovic, T., & Kisic-Tepavcevic, D. (2014). Parental knowledge, attitudes, and behaviors towards children with epilepsy in Belgrade (Serbia). *Epilepsy & Behavior, 41*, 210-216. https://doi.org/10.1016/j.yebeh.2014.09.062

Graham, C., Ballard, C., & Sham, P. (1997). Carers' knowledge of dementia, their coping strategies and morbidity. *International Journal of Geriatric Psychiatry, 12*(9), 931-936. https://doi.org/10.1002/(SICI)1099-1166(199709)12:9<931::AID-GPS666>3.0.CO;2-8

Ibinga, E., Ngoungou, E. B., Olliac, B., Hounsossou, C. H., Dalmay, F., Mouangue, G., ... & Druet-Cabanac, M. (2015). Impact of epilepsy on children and parents in Gabon. *Epilepsy & Behavior, 44,* 110-116. https://doi.org/10.1016/j.yebeh.2014.12.035

Jennum, P., Zoetmulder, M., Korbo, L., & Kjellberg, J. (2011). The health-related, social, and economic consequences of parkinsonism: a controlled national study. *Journal of Neurology, 258*, 1497-1506.

https://doi.org/10.1007/s00415-011-5969-1

Kayar, V., & Sahin, M. (2024). Adults' knowledge levels of and attitudes toward epilepsy: A cross-sectional study in Samsun Türkiye. *Neurology Asia, 29*(1), 87-96. https://doi.org/10.54029/2024mzr

Kuai, Y. H., Law, J. W. F., Ong, Y. S., Letchumanan, V., Lee, L. H., & Tan, L. T. H. (2024). Role of sara in staphylococcus aureus: A virulence target for therapeutic strategies. *Progress in Microbes & Molecular Biology, 7*(1). https://doi.org/10.36877/pmmb.a0000444

Letchemanan, B., & Low, H. M. (2024). Factors correlated with cognitive difficulties experienced by children with epilepsy. *Journal of Special Needs Education, 14*, 12-27. https://www.journal.nase.org.my/index.php/jsne/article/view/96. Accessed on 17th January, 2024.

Lin, J. J., Mula, M., & Hermann, B. P. (2012). Uncovering the neurobehavioural comorbidities of epilepsy over the lifespan. *The Lancet, 380*(9848), 1180-1192. https://doi.org/10.1016/S0140-6736(12)61455-X

Makhado, L., & Davhana-Maselesele, M. (2016). Knowledge and psychosocial wellbeing of nurses caring for people living with HIV/AIDS (PLWH). *Health SA Gesondheid, 21*, 1-10. https://doi.org/10.1016/j.hsag.2015.10.003

Modi, A. C. (2009). The impact of a new pediatric epilepsy diagnosis on parents: Parenting stress and activity patterns. *Epilepsy & Behavior, 14*(1), 237-242. https://doi.org/10.1016/j.yebeh.2008.10.009

Neni, S. W., Latif, A. Z. A., Wong, S. Y., & Lua, P. L. (2010). Awareness, knowledge and attitudes towards epilepsy among rural populations in East Coast Peninsular Malaysia: A preliminary exploration. *Seizure, 19*(5), 280-290. https://doi.org/10.1016/j.seizure.2010.04.006

Okiah, L., Olowo, S., Iramiot, S. J., Nekaka, R., & Ssenyonga, L. V. (2023). Lived experiences of caregivers of persons with epilepsy attending an epilepsy clinic at a tertiary hospital, eastern Uganda: A phenomenological approach. *PLoS One, 18*(7). https://doi.org/10.1371/journal.pone.0274373

Othman, A., Razak, S. A., Nasir, A., Ghazali, A. K., & Mohd Radzi, M. A. R. (2023). Depressive, anxiety, and stress symptoms in parents of children being admitted for febrile seizures in a tertiary hospital in the east coast of Malaysia. *European Journal of Investigation in Health, Psychology and Education, 13*(6), 1015-1025. https://doi.org/10.3390/ejihpe13060077

Oyegbile-Chidi, T., Harvey, D., Jones, J., Byars, A., Austin, J., Hermann, B., & Dunn, D. (2023). Impact of sociodemographic disadvantage on neurobehavioral outcomes in children with newly diagnosed seizures and their unaffected siblings over 36 months. *Epilepsia, 64*(8), 2172-2185. https://doi.org/10.1111/epi.17672

Rodenburg, R., Wagner, J. L., Austin, J. K., Kerr, M., & Dunn, D. W. (2011). Psychosocial issues for children with epilepsy. *Epilepsy & Behavior, 22*(1), 47-54. https://doi.org/10.1016/j.yebeh.2011.04.063

Saada, F., Wang, Z. S., & Bautista, R. E. D. (2015). In focus: The everyday lives of families of adult individuals with epilepsy. *Epilepsy & Behavior, 50*, 10-13. https://doi.org/10.1016/j.yebeh.2015.05.041

Saburi, G. (2011). Stressors of caregivers of school-age children with epilepsy and use of community resources. *Journal of Neuroscience Nursing, 43*(3), E1-E12. https://doi.org/10.1097/JNN.0b013e31821456f6

Thompson, R., Kerr, M., Glynn, M., & Linehan, C. (2014). Caring for a family member with intellectual disability and epilepsy: Practical, social and emotional perspectives. *Seizure, 23*(10), 856-863. https://doi.org/10.1016/j.seizure.2014.07.005

Ustuner Top, F., Cam, H. H., & Bora Güneş, N. (2024). Perceptions of stigma of children with epilepsy and their parents and its effects on social life. *Current Psychology, 43*(1), 62-71. https://doi.org/10.1007/s12144-023-04919-0

Vicars, M., & McKenna, T. (2015). In the thick of things: drama as a qualitative methodology. *Qualitative Research*

Journal, 15(4), 416-429. https://doi.org/10.1108/QRJ-06-2015-0034

Viny, M., Trevino, A. Y., Bouldin, E. D., Kalvesmaki, A., Roghani, A., & Pugh, M. J. (2023). Caregiver burden and COVID-19: How epilepsy caregivers experienced the pandemic. *Epilepsy & Behavior, 141*, 109151. https://doi.org/10.1016/j.yebeh.2023.109151

Wei, W., Yang, R., Zhang, J., Chen, H., Ye, J., Su, Q., ... & Xiao, Z. (2022). The mediating roles of family resilience and social support in the relationship between illness severity and depressive symptoms among primary caregivers of children with epilepsy in China. *Frontiers in Neurology, 13*, 831899. https://doi.org/10.3389/fneur.2022.831899

Wo, S. W., Ong, L. C., Low, W. Y., & Lai, P. S. M. (2018). Exploring the needs and challenges of parents and their children in childhood epilepsy care: A qualitative study. *Epilepsy & Behavior, 88*, 268-276. https://doi.org/10.1016/j.yebeh.2018.09.018

Yang, L., Ji, J., Lu, Q., Tang, P., Jiang, Y., Yang, H., & Tang, W. (2023). Caregivers' experiences in the management of children with epilepsy: A systematic synthesis of qualitative studies. *Seizure, 10*6, 117-128. https://doi.org/10.1016/j.seizure.2023.02.004