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KNOWLEDGE, ATTITUDE AND PRACTICE TOWARD EPILEPSY AMONG MOTHER WITH EPILEPSY CHILDREN IN PAEDIATRIC CLINIC, HOSPITAL UNIVERSITI SAINS MALAYSIA

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Abstract:
Aims. This study investigates the knowledge, attitudes, and practices of mothers caring for children with epilepsy, aiming to explore how these elements influence the care provided.
Background. The relationship among mother with Epilepsy Children but the knowledge, attitude and practise care remains the necessary knowledge to effectively manage epilepsy, prevent complications, and improve the overall quality of life for their children, in Paediatric Clinic, Hospital Universiti Sains Malaysia.
Design. The cross-sectional study involved 135 mothers who completed a comprehensive questionnaire.
Results. The majority of mothers (56.5%) demonstrate a strong understanding of epilepsy and engage in good seizure management practices (60.0%), their attitudes towards the condition are predominantly neutral (84.4%). Additionally, no significant correlation was found between maternal knowledge and educational level ($p > 0.05$).
Conclusions. These is a need for targeted educational interventions to improve attitudes and further support the effective management of epilepsy in children.

Keywords: *Epilepsy, maternal knowledge, caregiver attitudes, paediatric care, educational intervention , Malaysia.*

1.0 Introduction

Epilepsy, a chronic non-communicable brain disorder, affects approximately 50 million individuals globally, making it a significant public health concern (WHO, 2023). Each year, around 5 million people worldwide are newly diagnosed with epilepsy, with notable variations in incidence between high-income and low- and middle-income countries. In high-income regions, the annual incidence is about 49 per 100,000 people, whereas in low- and middle-income countries, it can reach up to 139 per 100,000 (WHO, 2023). This disparity highlights the global impact of epilepsy and underscores the need for tailored strategies to address the condition across diverse settings.

Epilepsy is defined by a persistent tendency to experience epileptic seizures, which can lead to a range of neurobiological, cognitive, psychological, and social consequences (Vancini et al., 2012). Seizures, characterized by involuntary movements that can be either partial or generalized, may sometimes involve loss of consciousness and control over bodily functions, such as bowel or bladder control (WHO, 2023). As one of the most common neurological disorders, epilepsy affects individuals regardless of age, gender, race, socioeconomic status, or geographic location (Adamu et al., 2023). Notably, epilepsy is the most prevalent serious neurological disorder in childhood, with prevalence rates ranging from 0.5% to 1.0% among children up to 16 years old (Aaberg et al., 2017). Each year, 200,000 new cases are diagnosed, with a significant number affecting children under 15 years of age. The incidence peaks in those younger than two years and those older than 65 (Goldenberg, 2010).

Epilepsy syndromes are categorized based on their aetiology and seizure manifestations. The causes of epilepsy include structural, genetic, infectious, metabolic, immune, and unknown factors, such as prenatal or perinatal brain damage, congenital abnormalities, head injuries, brain infections, or tumours (WHO, 2023). According to the International League against Epilepsy (ILAE), epilepsy is classified into four main types: focal, generalized, and combined generalized and focal, and unknown (Specchio et al., 2022). The classification further distinguishes between idiopathic epilepsy, which is of genetic origin with otherwise normal neurological function, symptomatic epilepsy, which has a documented cause, and presumed symptomatic epilepsy, where an underlying cause is suspected but not yet confirmed (Hahn, 2014).

Epilepsy often presents with temporary symptoms such as loss of awareness, disturbances in movement, sensation (including vision, hearing, and taste), mood, or other cognitive functions (WHO, 2023). Given the wide range of clinical presentations and the potential overlap with other medical conditions, accurate diagnosis relies heavily on detailed clinical history and observation of seizure events. The electroencephalogram (EEG) plays a pivotal role in identifying specific seizure types and epilepsy syndromes, thereby guiding prognosis and treatment.

Understanding the complexity of epilepsy and its varied manifestations is crucial for developing effective management strategies and improving patient. Understanding the complexity of epilepsy and its varied manifestations is crucial for developing effective management strategies and improving patient outcomes. This introduction provides a foundational overview of epilepsy, setting the stage for further exploration into its diagnosis, treatment, and impact on affected individuals and their families.

The rising prevalence of epilepsy among children, with incidence rates reaching 0.45% by age 5 and 0.66% by age 10 (Aaberg et al., 2017), underscores a critical public health concern. Notably, a nationwide Norwegian study reveals that approximately 80% of these children have at least one comorbid disorder (Aaberg et al., 2016). This complex health scenario places immense responsibility on parents, especially mothers, who are pivotal in managing their child's condition. Mothers, being the primary caregivers, possess an unparalleled understanding of their children and play a crucial role in their treatment and care.

However, there is a significant gap in understanding how mothers' knowledge of epilepsy influences their attitudes and practices. A lack of comprehensive knowledge can lead to inadequate management of the condition, resulting in potential risks such as poor safety practices, suboptimal medication adherence, and negative emotional impacts (Elafros et al., 2013). Despite advances in medical care and improved accessibility to healthcare services, the management of paediatric epilepsy heavily relies on the parents' understanding and approach (Sinha et al., 2023). Thus, investigating the level of knowledge, attitudes, and practices among mothers of children with epilepsy is crucial. Understanding these dimensions will help identify gaps in parental education and support systems, ultimately aiming to enhance the care and outcomes for both the children and their families. This study is essential to ensure that mothers are equipped with the necessary knowledge to effectively manage epilepsy, prevent complications, and improve the overall quality of life for their children.

2.0 Back ground of the study

An intensive literature informed this study's prevalence of epilepsy in children approximately 0.5% of children experience epilepsy during their childhood and in the industrialized nations, there is an average of approximately 50 new cases of epilepsy per 100,000 children annually and about 25% of children were newly diagnosed with epilepsy (Hahn, Fisher et al., 2014). 2014). The United States, including both adults and children, is on the rise, with a minimum of 3.4 million people affected by the disorder, and the number of children with epilepsy increased from 450,000 in 2007 to 470,000 in 2015 (Zack & Kobau, 2017). In both of these USA studies, epilepsy was found to be more common in children from families with income below the US federal poverty level (Camfield & Camfield, 2015). The prevalence of epilepsy in children is twice as high as in adults, with a rate of seven in 1000 among children ((Beghi, 2020)., Kolahi et al., 2017).According to the International League Against Epilepsy (ILAE), epilepsy is a disease of the brain causing at least two unprovoked or reflex seizures occurring more than 24 hours apart or after one seizure if risks of occurrence are high.

Age of children with epilepsy

Studies on the incidence of epilepsy in children typically focus on cases of new-onset epilepsy occurring before the age of 16 (Camfield & Camfield, 2015). In children, the incidence of epilepsy is highest in the first year of life and declines to adult levels by the end of 10 years of age (Beghi, 2020). Age of onset was significantly correlated with aetiology in children with epilepsy. About 28% of the children were structural or metabolic, which predominated when seizures started before 12 months of age, and 22% were presumed genetic, most likely associated with older age at onset (Wirrell et al., 2011). Epidemiological studies often report age-specific incidence rates for children with epilepsy onset up to five years of age - termed here as children with early-onset epilepsy (CWEOE; onset before the fifth birthday (< 60 months)), but there are few population based studies that have focused on the epidemiology of CWEOE and only limited data exist (Hunter et al., 2020). Based on a study of epilepsy according to the age at onset in Spain, it was found that the most prevalent aetiology in children with early onset was symptomatic (67.09% of children with onset before 1 year and 61.39% of children with onset at age 1-3 years). Idiopathic epilepsy predominated in children with onset between 6 and 10 years of age (43.75%), and cryptogenic in children with onset between 3 and 6 years of age (43.10%) (Ochoa-Gómez et al., 2017). Thus, epilepsy is age-dependent, it is very important to get know the characteristics of different epilepsy types in each group for identifying and managing epilepsy effectively, minimizing the need for unnecessary diagnostic tests, commencing appropriate antiepileptic treatment, and providing families of children with epilepsy a reliable prognosis.

Morbidity and Mortality of epilepsy in children

Childhood epilepsy is associated with significant morbidities due to underlying brain diseases and the risk of epileptic seizure (Jennum et al., 2017). Based on nationwide Norwegian registry study, approximately 80% of children diagnosed with epilepsy also had at least one comorbid disorder and children with epilepsy exhibited a higher prevalence of various types of disorders, with 55% experiencing additional medical disorders, 41% having neurologic disorders, and 43% having developmental and psychiatric disorders (Aberg et al., 2016). Neurodevelopmental and psychiatric comorbidities, including conditions such as intellectual disability (ID), attention-deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), behavioural disorders, and emotional disorders, have been identified in over 40% of children with epilepsy and these comorbidities can significantly influence their education, quality of life (QOL), and have long term effects on their adult lives (Reilly et al., 2014). Furthermore, epilepsy compromises the quality of life of patients including daily duties through emotional and cognitive development to self-image and relationships with other people (Rozensztrauch & Kołtuniuk, 2022). According to World Health Organization 2023, epilepsy accounts over 0.5% of the worldwide disease burden, as measured by a composite index that factors in both years of life lost due to premature death and years lived with compromised health. Mortality rates in people with epilepsy are 2 to 4 times higher in overall and 5-10 times higher in paediatric epilepsy (Nickels et al., 2013). Individuals with epilepsy experience elevated mortality rates due to various factors, including the progression of their underlying condition, seizure related accidents, suicide, status epilepticus, aspiration during seizures, and sudden unexplained death in epilepsy (Ficker, 2000).

A published cohort of children with epilepsy that was conducted in Tunku University Hospital Finland, (including both prevalent and incident cases) reported an overall mortality rate of 6.9 deaths per 1,000 person-years (Shinnar, 2010). A study about deaths in children with epilepsy also conducted in United Kingdom, it was found that a total of 46 deaths in children with epilepsy were notified to the study (Sidebotham et al., 2015). However, improvement in the diagnosis, treatment, and management of children with epilepsy have the potential to reduce the preventable deaths, including sudden unexpected death in epilepsy, as well as reduce healthcare resource utilization, and address cognitive, emotional, and behavioural challenges (Myland et al., 2019).

Treatment of epilepsy

Epilepsy is one of the most common serious neurological disorders and is prevalent in 0.5% of UK children (Myland et al., 2019). Epilepsy is a treatable condition, with up to 80% entering prolonged periods of seizure remission and up to 50% continuing to be seizure-free after treatment discontinuation (Sillanpää & Schmidt, 2006). Antiepileptic medications (AEDs) have become the initial treatment choice for almost all patients with multiple seizures. Antiepileptic drugs (AEDs) are medications that reduce the frequency or intensity of seizures in individuals with epilepsy (Bromfield et al., 2023). The main objectives of AEDs treatment are to evade the adverse effects associated with long treatment, to aid patients in maintaining or restoring their usual psychosocial and vocational activities, and maintaining a normal lifestyle (Goldenberg, 2010). These medications are designed to manage the symptoms of epilepsy rather than addressing the root cause of the condition. The choice to initiate AED therapy should stem from a well-informed assessment of several factors, including the probability of seizure recurrence, the impact of ongoing seizures on patients, and the advantages and potential adverse effects associated with the selected pharmaceutical treatment (Goldenberg, 2010). The older and most commonly used medications in the treatment of childhood epilepsy are sodium valproate and carbamazepine. Phenytoin and phenobarbitone, previously drugs that mostly used for most seizure types no longer considered to be first, second, or third line drugs due to their unsatisfactory long-term safety profile (Appleton & Cross, 2012).

Knowledge toward epilepsy among mothers with epilepsy children

Knowledge is a crucial component when it comes to taking care of children with epilepsy. Comprehensive knowledge of a disease involves possessing sufficient and relevant information about its clinical manifestations, treatment options, and potential outcomes (Eseigbe et al., 2015). A mother’s knowledge about epilepsy is essential for her child's safety, well-being, and overall quality of life thus empowers her to make informed decisions, provide appropriate care, and advocate for her child's needs, ultimately ensuring the best possible outcomes for the child. Since epilepsy is characterized by recurrent seizures, children with epilepsy need to seek treatment from time to time by a healthcare professional and mothers play an important role in managing their epilepsy child. Furthermore, epilepsy is also one of the chronic disorders and needs long-term treatment. According to a study to assess parent’s knowledge of epilepsy in their children at Paediatric Clinic in Universiti Kebangsaan Malaysia, a total of 45 parents (90%) were unaware of their children's type of epilepsy, twenty-five parents (50%) responded to underlying cause of epilepsy as 'don't know'. One of the remaining who responded positively, 32% (8/25) attributed it to brain disease, 8% (2/25) to birth defects and 12% (3/25) to fever. An epileptic attack was seen as a convulsive episode by 78% (39/50) parents and 4% (2/50) of parents thought that it was a period of loss of consciousness and 2% (1/50) stated that it was change of behaviour (Norzila et al., 1997). The knowledge toward epilepsy among children also was assessed in Abha City, Kingdom of Saudi Arabia show that all the included parents rated the word epilepsy as common for them. Most of the subjects knows that epilepsy can be treated (84.3%), 90.9% knew that epilepsy is associated with hereditary and all of them correctly knew that epilepsy is not a contagious disease as well as 52.5% recognized that epilepsy can be caused by trauma or stroke. Furthermore, only 37.5 % had good knowledge about not considering epilepsy as mental or psychiatric disease and only 21.1% knew that epilepsy could be treated by surgery. Thus, the knowledge of most of the respondent was adequate which is about 68.2% (Hussamaldin Tariq A, 2018).

According to a study conducted in Mofid Children's hospital in Tehran, Iran, it was found that the level of knowledge of 69.2% mothers was good, 27.7% fair, and 3.1% poor. Approximately 90% of mothers were informed that epilepsy is categorized as a neurological condition, while 60% were aware that it is distinct from psychiatric disorders (Kolahi et al., 2017). Based on the study was carried out at Smouha Health Insurance Child Mental Health in Alexandria, Egypt to assess level of mother's knowledge about childhood epilepsy, it was found that the majority of mothers (80.5%) had unsatisfactory knowledge, while none of them showed highly satisfactory knowledge. The majority of items displayed the highest percentages in an inaccurate manner (Ibrahim & Shata, 2017). However, based on the data from the previous study, the level of mother's knowledge and understanding toward epilepsy still need to be improved.

Attitude toward epilepsy among mothers with epilepsy children

The attitude of a mother toward an epilepsy child refers to the mother's overall perspective, beliefs, feelings, and behaviours regarding her child who has epilepsy. It involved how the mothers perceive and interact with their sick child and alert about their health condition which significantly affects the overall child's wellbeing and the management of epilepsy. A positive attitude shown by the mothers can adversely be beneficial for the child's development which can lead to good quality of life and reduce the negative stigmatization toward the child with epilepsy. Parental attitudes appear to be significantly linked to epilepsy-related challenges in children, influencing factors such as the duration and severity of seizures and this could potentially impact the behavioural and psychological well-being of the children (Hussamaldin Tariq A, 2018).

A study was conducted at Smouha Health Insurance Child Mental Health in Alexandria, Egypt to assess the attitude among mother toward their epilepsy children and it was found that the majority of mothers (91.9%) agreed that they could observe their children all the time to ensure their child's safety. A majority of mothers, about (66.6%), believed that they should avoid discussing their illness with their children and about (54.2%) of mothers expressed disagreement about allowing their children to participate in household chores, and (52.3%) of them acknowledged that they did not treat their child as normal child, while about 1.9% admitted to actively rejecting their child, while the rest displayed overprotective behaviour.

A minority of mothers, specifically 42.9%, believed that they should restrict their children from engaging in hobbies or sports to ensure safety and in contrast, only 1.9% of mothers admitted to concealing their child's illness from everyone, while the majority (75.3%) did not conceal it at all (Ibrahim & Shata, 2017). According to study that conducted in Abha City, Kingdom of Saudi Arabia, it shown that most of the respondents shows positive attitude toward the ability of the epileptic child to live and learn equally in the society (93.6%). Moreover, (68.6%) of respondents concurred that epilepsy does not significantly impact daily activities, while (57.5%) indicated that the intelligence of individuals with epilepsy remains unaffected.

Furthermore, all participants expressed a positive attitude towards not viewing individuals with epilepsy as obstacles in society (Hussamaldin Tariq A, 2018). A study also conducted in University Malaya Medical Centre, Kuala Lumpur to assess attitude among Malaysian parents of children with epilepsy found that the majority of the parents had positive to very positive attitude which is (85.9%) and found that a large proportion (86%) of parents had positive attitudes toward their epilepsy child (Yi et al., 2019). Based on study conducted in Iran to assess the attitude among mothers with epilepsy child, it shown that mother’s attitude toward children with epilepsy were mainly positive. Among the mothers who answered questions on this subject, the majority did not experience shame regarding their children's illness, and about (98.5%) of mothers were open to sharing information about their children's condition with others. Mothers that participated in this study experienced reduced stigma associated with epilepsy, which differs from another study where approximately one-fifth of mothers reported feeling stigmatized due to their children's epilepsy (Kolahi et al., 2017). The latter study suggested that increased education and better knowledge about epilepsy could potentially reduce stigma levels (Elafros, Sakubita-simasiku, et al., 2013).

Practice toward epilepsy among mothers with epilepsy children

The practice of a mother can encompass a wide range of responsibilities and activities related to caring for her children and family. The practice of a mother also refers to the specific actions and responsibilities a mother undertakes when her child is unwell or dealing with a medical condition. Managing a child with epilepsy involves a range of activities and decisions that are focused on the child's health and well-being. Delay or inappropriate management of acute seizures may have serious hazardous consequences with subsequent brain damages or even death (Elsakka et al., 2021).

According to study in Egypt, regarding the practice during the acute seizure attack and home management, it shown that more than half (66.8%) of parents with epilepsy children showed poor score percentage, (26.5%) showed fair score percentage, and only (6.7%) showed good percentage (Elsakka et al., 2021). A study also conducted in Abha City, Saudi Arabia, it found that more than half of participants would call the ambulance for convulsing child (51.6%), most of them would follow up with doctor (82.7%) and about (84.8%) will act normally with relatives or epileptic persons. This study also includes the practice of the mother when experiencing the child suffering from convulsion and the reaction toward the epileptic child, thus the practice score was adequate among (72.5%) of the parents (Hussamaldin Tariq A, 2018).

Based on a study in Sudan to assess the practice of caregiver of epilepsy children, it shown among 107 caregivers, about 78 (72.9%) had witnessed generalized tonic-clonic seizures of their children. It also showed the frequency of the caregiver's first aid measures used during generalized tonic-clonic seizures. Slightly less than half of these caregivers, specifically (39.7%), repositioned their child onto one side during a seizure and about 37.2% of caregivers acknowledged that they sprinkled water over the child during a seizure (El-amin et al., 2021).

In contrast, most of the parents (71.5) in study from Jordan, knew the lateral positioning is recommended when a child is seizing. Furthermore, this study also reflects that most caregivers have a high chance of mishandling children with epilepsy in emergency situations. Thus, it indicates the importance of healthcare professionals prioritizing the education of caregivers regarding essential first aid procedures. Another study in Iran to assess practices among mothers of with epilepsy children, the result showed that among 206 mothers, about 170 (82.5) had witnessed the generalized seizures of their children. However, nearly one-third of them attempted to physically restrain their children during a seizure, which can potentially become life-threatening to the children. This study also highlights the frequency of mother's first aid used at the last seizure. Based on this study, the practice score of 19.3% of mothers was very good, 57.8% good, and 22.9% and no mothers had poor levels of practice. The majority of mothers was about (79.2%) had taken their children to the hospital after experiencing seizure.

Theoretical and conceptual Framework of the study

Health Belief Model (HBM) is a cognitive framework that suggests an individual's behaviour can be influenced by their perceptions of health risks and their beliefs regarding their well-being, as well as the anticipated effectiveness and outcomes of specific actions or behaviours (Becker, 1974; Rosen stock, 1974). The HBM aims to predict health related behaviours in terms of certain belief patterns (Rebecca Wolfe Acosta & Wolfe, 2008). This model is divided into three categories which are individual perceptions, modifying factors, and likelihood of action. Individual perception is the main factor that affects the perception of illness and the importance of health to the individual perceived susceptibility and perceived severity of the disease. For modifying factors, it includes the sociodemographic variables (such as age, sex, race, or ethnicity), perceived threat of the disease, and cues to the action. The likelihood action involves perceived benefits of preventive action or perceived barrier to preventive action. Strengths The main strength of the HBM is its use of simplified health-related constructs that make it easy to implement, apply, and test and it has provided a useful theoretical framework for investigating the cognitive determinants of a wide range of behaviours for over three decades (Orji et al., 2012).The HBM contains several primary concepts that predict the reason. HBM predicts people perceive to be susceptible to particular health problems may engage in behaviours that may reduce the risk of developing health problems (Tshababa et al., 2020). Regarding to my study, when a family perceives a heightened risk of experiencing epilepsy, they are more likely to adopt behaviours aimed at reducing the chances of developing this health issue. Furthermore, for perceived benefits promote people with epilepsy to be engaged in health seeking behaviours to decrease the risk of health problem. For perceived barriers, an individual living with epilepsy may perceive a certain health condition as menacing and hold the belief that specific actions can effectively mitigate this threat. However, various obstacles may hinder their ability to engage in health promoting behaviours.

3.0 Methodology

Research study

Aim

The study aimed to determine the level of knowledge, attitude, and practice toward epilepsy among mothers with epilepsy children in paediatric clinic, Hospital Universiti Sains Malaysia.

Design

Cross-sectional design was used in this study. This research design is used to investigate the measurement of outcome and the exposure of respondents at the same time based on researcher's objective. This approach also considered appropriate to give a detailed description of the participant's knowledge, attitude, and practice toward epilepsy among mothers with epilepsy children in paediatric clinic, Hospital Universiti Sains Malaysia.

Sample

This study used a purposive sampling method for the collection of data. Purposive sampling represents a group of different non-probability sampling techniques and relies on the judgement of the researcher when it comes to selecting the unit (people, cases/organizations, pieces of data) to be studied (Rai & Thapa, 2019). Purposive sampling aims to help to concentrate on specific characteristics of a population of interest and enable the participants to answer the research questions. Instead of being randomly selected from a larger population, participants in this approach are chosen because they are readily accessible to the researcher. The participants from this study were selected from those who had full fill inclusion and exclusion criteria. This method was used to collect the data in paediatric clinic, Hospital Universiti Sains Malaysia. The sample size is calculated for all the objectives in this study. Objectives 1,2, and 3 used single proportion formula. n= required sample size .$z\alpha$= Value of the standard normal distribution curve cutting off probability Alpha (α) in one tail for one-sided alternative or $\alpha 2$ in each tail for a two-sided alternative (z0.05=1.96) . $z\beta$= Power of study, 80% (zβ = 0.84) . p= Estimated proportion of an attribute that is present in the population .$p1$= High educational level, 0.45 .$p2$= Low educational level, 0.23 .$0.45(1 - 0.45) + 0.23(1 - 0.23)(1.96 + 0.8$.$n = (0.45 - 0.23)_2$ / n = 33.2 n = 33 participants per group after considering 10% of drop out, n = 10% x 33 n = 3 n= 33 + n =36 sample size **study** translation method.

Validity and Reliability

The questionnaire is adopted from studies that have been carried out previously, conducted (Kolahi et al., 2017) and permission was taken (refer to appendix B). The questionnaires were divided into three parts as explained as follows: **Section A: Socio-demographic data** Section A consists of sociodemographic questions including name, age, religion, ethnicity, education level, marital status, occupation, household income, and number of children. **Section B: Knowledge toward epilepsy among mothers Section** B included 38 questions regarding prevalence and general knowledge about epilepsy (consist of 12 questions), aetiology of epilepsy (consist of 13 questions), and possible symptoms of epilepsy (consist of 13 questions). **Section C: Attitude toward epilepsy among mothers S**ection C included 20 questions regarding mother's attitudes towards epilepsy and patients with the disease. **Section D: Practice toward epilepsy among mothers; Section** D section included 14 questions about first-aid measures taken by mothers who had witnessed generalized epilepsy or last seizure by the time of the interview. **Translation of Instrument** The original questionnaire was established in English. Since this study was conducted in a general population, which are mothers with different educational backgrounds, the questionnaires were translated into the Malay version using backward

Validity and reliability of instrument is a crucial element to ensure a good measurement in research and provide accurate an accurate result. Appropriate questions for assessment of the knowledge, attitudes, and practices of mothers were developed using previously published studies investigating parents, patients with epilepsy, health care professionals, teachers, students, and the public. The questionnaire was sent with the original version to the Pusat Pengajian Bahasa, Literasi & Terjemahan, and Health Campus together with the original version for final check by a bilingual expert to ensure its accuracy. Following this, the translated version was checked by two nursing lecturers and one paediatric doctor. In order to ensure the reliability of the questionnaire, a pilot study was conducted about 10% of the sample size among mothers in the medical paediatric ward (6 Selatan) and those mothers were excluded from the main study. The acceptable values of Cronbach’s alpha reliability ranging from 0.70 to 0.95 (Tavakol & Dennick, 2011).

Measurement of Variables and Variable Scoring : For **mother's knowledge** regarding epilepsy items which include the general knowledge about epilepsy, aetiology, and symptoms of seizures, one point was awarded to each correct answer. The total knowledge score of mothers related to epilepsy varied from 0-38. Based on the mother's knowledge score percentiles, their level of knowledge about epilepsy was categorized as very low for 40th percentile or poor; fair 41-60; good 61-80; and very good for more than 80 (Kolahi et al., 2018).

For **mother's attitudes** items, it consists of 20 questions and use Likert scales (Strongly disagree, Disagree, No opinion, Agree, Strongly agree) where the minimal score 1 denoted for "strongly disagree" and the maximal mark 5 denoted "strongly agree". Bloom cut off point will be used to categorize each answer. In the section of attitude, respondents' was identified as "positive" if the score was between more than 75%, "neutral" if the score was between 50-75% and "poor" if the score was less than 50% (Elsakka et al., 2021). For **mother's practice** items, at the time of the last seizure were categorized as helpful or potentially harmful, one point was awarded to taking each helpful measure or not taking each harmful measure. Therefore, the total score in this section varied from 0 to 14. Based on mother's score percentiles, their score level regarding first-aid measures at time of the last witnessed seizure was categorized as poor for 50th percentile or lower; good 51-75; and very good for more than 75 (Kolahi et al., 2018).

4.0 Data Collection

The data collection was started from January to March 2024 after obtaining ethical approval from the Human Research Ethics Committee (HREC), USM. **Data Analysis** Data collection was analysed using Statistical Package for Social Sciences Software (SPSS) version 27.0. The sociodemographic data was analysed using descriptive statistics. Descriptive analysis To identify the level of knowledge toward epilepsy among mothers with epilepsy children in pediatric clinic, Hospital Universiti Sains Malaysia To identify the level of attitude toward epilepsy among mothers with epilepsy children in pediatric clinic, Hospital Universiti Sains To identify the level of practice toward epilepsy among mothers with epilepsy children in pediatric clinic, Hospital Universiti Sains. To identify the association between knowledge and sociodemographic factors (educational level) toward epilepsy among mothers with epilepsy children in pediatric clinic, Hospital Universiti Sains Malaysia.

4.1 Ethical consideration

The approval from the Human Research Ethics Committee (HREC), USM was obtained before starting the data collection. Approval of study location was obtained from

Director of Hospital Universiti Sains Malaysia to gain the access of the study population, mothers with epilepsy child in paediatric clinic.

4.1.2 Results.

Participant's demographic variable

This study included 135 participants, with the majority aged between 30-39 years (41.5%), followed by those aged 18-29 (40%), and 40-49 (18.5%). Most participants were Malay (97.8%) and Muslim (97%). In terms of education, the largest group had tertiary education (75.6%), followed by secondary (23%), and a small percentage had only primary education (1.5%). All participants were married. Employment status showed that 64.4% were unemployed, while 35.6% were employed. Regarding household income, 68.9% earned less than RM4, 850, 27.4% earned between RM4, 850 and RM10, 959, and only 3.7% earned more than RM10, 959. The majority of participants had fewer than three children (78.5%), while 21.5% had more than four children (Table 1).

Table 1: Survey participants' demographic variables.

Variables	n (%)
Age	
18-29	54 (40%)
30-39	56 (41.5)
40-49	25 (18.5)
Ethnicity	
Malay	132 (97.8)
Chinese	3 (2.2%)
Religion	
Muslim	131 (97%)
Buddhist	1 (0.7%)
Christian	3 (2.2%)
Education level	
Primary	2 (1.5%)
Secondary	31 (23%)
Tertiary	12 (75.6%)
Marital status	
Married	135 (100%)
Divorced	0
Occupation	
Employed	48 (35.6%)

Unemployed	87 (64.4%)
Household income	
Less than RM4,850	93 (68.9%)
RM4,850-RM10,959	37 (27.4%)
More than RM10,959	5 (3.7%)
Number of children	
Less than 3	106 (78.5%)
More than 4	29 (21.5%)

Level of knowledge toward epilepsy among mothers with epilepsy children in paediatric clinic, Hospital Universiti Sains Malaysia.

Results on the level of knowledge among mothers with epilepsy children in paediatric clinic, Hospital Universiti Sains Malaysia were shown in table 2. Regarding general knowledge of epilepsy, about 83.1% of mothers knew that epilepsy is a neurological disorder which can be treated by regular drug therapy and about 81.5% of them are aware that epilepsy is noncontagious disease. About 51.9% of mothers knew that the medications cannot be drawn immediately once being seizure free and about

Statement	It is true (%)	It is false (%)	No idea (%)
Epilepsy is a neurological disorder	112 (83%)	5 (3.7%)	18 (3.3%)
Epilepsy is treatable	107 (79.3%)	10 (7.4%)	18 (13.3%)
Most seizures are controlled after regular drug therapy	91 (67.4%)	11 (8.1%)	33 (24.4%)
There are different types of epilepsy	107 (79.3%)	5 (3.75)	23 (17%)
Some seizures may last a few seconds and not be sensed by others	104 (77%)	10 (7.4%)	21 (15.6)
Some patients may sense an upcoming seizure shortly before it happens	76 (56.3%)	14 (10.4%)	45 (33.3%)
Some children with epilepsy may need to follow special diets to prevent seizure	53 (39.3%)	28 (20.7%)	54 (40%)
A normal EEG rules out epilepsy	19 (14.1%)	39 (28.9%)	77 (57%)

Once being seizure- free, the medications can be withdrawn immediately	26 (19.3%)	70 (51.9%)	39 (28.9%)

Statement	It is true (%)	It is false (%)	No idea (%)
All patients need to take lifelong medications	57 (42.2%)	43 (31.9%)	35 (25.9%)
Epilepsy is a psychological disorder	28 (20.7%)	63 (46.7%)	44 (32.6%)
Epilepsy is a contagious disease	7 (5.2%)	110 (81.5%)	18 (13.3%)

42.2% mentioned all patients need to take lifelong medications.

Table 2: Frequency and percentage of knowledge toward epilepsy among mothers with epilepsy children in paediatric clinic, Hospital Universiti Sains Malaysia (general knowledge of epilepsy).

In response to the questions about causes of epilepsy, about 94.1 % and 76.3% considered brain tumour and genetic influence to be possible causes of their children's disease. In addition, almost 69.6% denied demonic possession as the cause of epilepsy, however majority 89.6% of mother mentioned dementia as the cause of epilepsy. Overall, mothers' knowledge about symptoms of seizures was good. They acknowledge the important symptoms of seizures, loss of consciousness, foaming at the mouth, tongue biting and body jerks. About 66% of the mothers did not consider urinary incontinence as the possible events at the onset of seizures.

Table 3: Frequency and percentage of knowledge toward epilepsy among mothers with epilepsy children in paediatric clinic, Hospital Universiti Sains Malaysia (possible symptoms of seizure)

Event at the onset of seizures	**Yes (%)**	**No (%)**	**No idea (%)**
Loss of consciousness	121 (89.6%)	10 (7.4%)	4 (3.0%)
Foaming at the mouth	122 (90.4%)	6 (4.4%)	7 (5.2%)
Sleeping after seizure	79 (58.5%)	19 (14.1%)	37 (27.4%)
Stiffness	116 (85.9%)	7 (5.2%)	12 (8.9%)

Event at the onset of seizures	Yes (%)	No (%)	No idea (%)
Urinary incontinence	54 (40.0%)	15 (11.1%)	66 (48.9%)
Tongue biting	121 (89.6%)	6 (4.4%)	8 (5.9%)
Tonic-clonic seizure	87 (64.4%)	8 (5.9%)	40 (29.6%)
Body jerks	116 (85.9%)	5 (3.7%)	14 (10.4%)
Tremor	110 (81.5%)	6 (4.4%)	19 (14.1%)
Staring	91 (67.4%)	29 (21.5%)	15 (11.1%)
Falling	114 (84.4%)	10 (7.4%)	11 (8.1%)
Head drop	112 (83.0%)	11 (8.1%)	12 (8.9%)
Confusion	97 (71.9%)	18 (13.3%)	20 (14.8%)

Table 3 depicts the overall level of knowledge and frequency among mothers with epilepsy children in paediatric clinic, Hospital Universiti Sains Malaysia. Majority of mother have good knowledge, 76 (56.3%), about 28 (20.7%) have very good knowledge, while 27 (20%) have fair knowledge and only 4 (3.0%) of mothers have poor knowledge regarding epilepsy. Table Level of knowledge toward epilepsy among mothers with epilepsy children in Paediatric clinic, Hospital Universiti Sains Malaysia.

Level of attitude toward epilepsy among mothers with epilepsy child in paediatric Clinic, Hospital Universiti Sains Malaysia

Results on mothers' attitude were shown in table 4. About 61.5% of mothers agree that parents should inform schoolteachers of their children's disease and about 54.8% of mothers strongly agree that patient with epilepsy should inform their spouses before marriage. Majority 53.3% of mother disagree that patients with epilepsy can never reach high education levels and 39.3% disagree that patients should lower the expectations of the children with epilepsy. Moreover, they did not tend to limit their children's activities and were optimistic about their future. Majority 28.9% of mothers had no opinion about society discriminates against people with epilepsy. About 46.7% of mothers disagreed about being ashamed of having a child with epilepsy and were not against informing others about their children's condition. Almost half 50.4% of mothers disagreed that children with epilepsy should hide their disease and majority 48.9% disagreed that patient with epilepsy would better not have kids. Hence, overall mother's attitude was neutral which 84.4% is and only 4.4% of them have good attitude regarding epilepsy.

Table 4. Level of attitude toward epilepsy among mothers with epilepsy children in paediatric clinic, Hospital Universiti Sains Malaysia

Level of attitude	Frequency (%)	Mean ± SD
Negative attitude	15 (11.1%)	
Neutral attitude	114 (84.4%)	
Positive attitude	6 (4.4%)	58.73 ± 8.75
Total	135 (100.0%)	

Level of practice toward epilepsy among mothers with epilepsy child in paediatric clinic, Hospital Universiti Sains Malaysia

Results on practice among mothers were shown in Table 5. Mothers' practices

at time of the last seizure are categorized as helpful or harmful. Almost 99.3% of mothers informing their fathers or others when the child is experiencing seizure and about 94.1% taking them immediately to the hospital after seizures. Majority 98.5% of mothers putting away sharp things around their children during seizure and about 94.8% of them were preventing their children from falling. Most mothers practice helpful measures when their children are experiencing seizure. However, about 62.2% of mothers tried to hold their children to stop the seizure, which could have life threatening consequences. Majority 68.9% of mother attempting to open their mouth to put something between jaws during seizure attack which can be potentially harmful to the children. Therefore, overall mother’s practice during last seizure was good which 60.0% is and only 2.2% have poor practice regarding the last seizure.

Table 5. Frequency and percentage of practice toward epilepsy among mothers with epilepsy children in pediatric clinic, Hospital Universiti Sains Malaysia

Measures	**Yes (%)**	**No (%)**
Helpful measures		
Informing their fathers or others	134 (99.3%)	1 (0.7%)
Taking them to the hospital after seizures	127 (94.1%)	8 (5.9%)
Putting away sharp things around their children	133 (98.5%)	2 (1.5%)
Preventing them from falling	128 (94.8%)	7 (5.2%)

Loosening pieces of clothing around their neck	125 (92.6%)	9 (6.7%)

Table 6 Level of practice toward epilepsy among mothers with epilepsy children in paediatric clinic, Hospital Universiti Sains Malaysia

		Frequency (%)	Mean ± SD
Level of practice			
	Poor practice	3 (2.2%)	
	Good practice	81 (60.0%)	9.96 ± 1.80
	Very Good practice	51 (37.8%)	
	Total	135 (100.0%)	

5.0 DISCUSSION

Based on the outcome of this study, overall mean score for the level of knowledge among mothers with epilepsy children is 25.68 (SD = 4.6). Most of the mothers have good knowledge about epilepsy, with 56.3% demonstrating solid understanding. Additionally, 20.7% have very good knowledge, 20% have fair knowledge, and only 3.0% of mothers have poor knowledge regarding epilepsy. This evidence by majority 83.1% of mothers knew that epilepsy is a neurological disorder that can be treated with regular drug therapy, and about 81.5% were aware that epilepsy is a noncontagious disease. Most mothers have good access to health information in HUSM and receive information about epilepsy from the physicians that been treating their children in the pediatric clinic. Based on the Health Belief Model used in this study, cues of action or external cues, such as professional advice, can reinforce or enhance a mother's knowledge, thereby guiding her practical actions. Previous study from the original questionnaire (Kolahi et al., 2017), the finding shows that the mean (SD) knowledge score of mothers about epilepsy was 24.6 (SD = 6.3). Align this study, the level of knowledge of majority 69.2% mothers was good, 27.7% fair, and 3.1% poor. Almost 90% of mothers knew that epilepsy is neurological disorder, and 60% knew that epilepsy is not a psychiatric disorder and thus in line with a study conducted in Serbia that also found about 68% of mothers understood that epilepsy is not a psychiatric disease. Physicians and nurses were the primary sources of information about epilepsy while teachers, schools, and the internet played a lesser role in educating mothers about the condition (Kolahi et al., 2017).

Based on a study in Saudi Arabia, most respondents had adequate knowledge, with about 68.2% understanding that epilepsy can be treated, 84.3% knew that epilepsy is treatable, 90.9% recognized its hereditary association, and all mothers correctly identified that epilepsy is not a contagious disease and 52.5% were aware that epilepsy can be caused by trauma or stroke (Hussamaldin Tariq A, 2018). In contrast, a study conducted in Egypt found that the majority of mothers (80.5%) had unsatisfactory knowledge, with none demonstrating highly satisfactory knowledge (Ibrahim & Shata, 2017). Differences in knowledge levels can varied from various factors, such as the study setting (whether in a developed or developing country), the educational level of caregivers, the routine provision of educational services by care providers, methodological variations, and cultural and social influences (Ibrahim & Shata, 2017).

Based on the outcome of this study, the overall mother’s attitude was neutral which 84.4% is, about 11.1% have negative attitude only 4.4% of them have good attitude regarding epilepsy. In contrast, previous study from the original questionnaire (Kolahi et al., 2017) found that mothers' attitudes towards patients with epilepsy were mainly positive. The majority of mothers were against the idea that patients with epilepsy should hide their disease and stated that parents should inform schoolteachers of their children's disease, aligning with the study findings. The finding in this study shows that almost 53.3% of mother disagree that patients with epilepsy can never reach high education levels and 39.3% disagree that patients should lower the expectations of the children with epilepsy. Compared with previous study in Malaysia, majority (86%) of the parents had positive attitude toward their epilepsy child, with (99%) of them agree that their children can socialize in the community and (87%) agree that their children can participate in sports (Yi et al., 2019). In contrast, study in Saudi Arabia by (Hussamaldin Tariq A, 2018), attitude score was adequate among (76.4%) of the parents, with (68.6%) of respondent agreeing that epilepsy does not significantly impact daily activities and (57.5%) indicated that the intelligence of individuals with epilepsy remains unaffected. Based on Health Belief Model used in this study, knowledge about epilepsy directly impacts on mother’s attitudes. Well-informed mothers are more likely to have a positive attitude towards managing epilepsy and education level plays a crucial role in shaping this knowledge. Thus, mother’s experiences and understanding about epilepsy foster positive attitudes, leading to better management and coping strategies.

Furthermore, mothers’ attitude towards managing their children with epilepsy is influenced by experience exposure, social support, and stigma. Experience exposure which gained through dealing with their or interacting with other families in similar situations, helps mothers develop more positive attitude. Social support from family, friends, and healthcare provider plays important role in shaping their attitude. However, stigma associated with epilepsy can negatively impact mother’s attitude and thus lead to feelings of shame, guilt, and helplessness.

Based on the outcome of this study, mean score for the level of knowledge among mothers with epilepsy children is 9.96 (SD = 1.8) with overall mother's practice during last seizure was good which is 60.0%, about 37.8% have very good practice and only 2.2% have poor practice. Based on previous study from the original questionnaire (Kolahi et al., 2017), the mean practice score of mothers is 8.8 (SD= 1.8) with the finding shows, practice score of 19.3% of mothers was very good, 57.8% good, and 22.9% fair. This is evidenced by majority of the mothers (94.1%) had taken their children to the hospital right away after seizure and about (98.5%) of them putting away sharp things around their children during seizure. This aligns with the study from (Hussamaldin Tariq A, 2018), which about (72.5%) of mothers show adequate practice score, with more than half of the participants would call ambulance for convulsing child (51.6%), most of them would follow up with a doctor (82.7%) and 84.8% will act normally with relatives or epileptic persons.

In contrast, according to study in Egypt, regarding the practice during the acute seizure attack and home management, it shown that more than half (66.8%) of parents with epilepsy children showed poor score percentage, (26.5%) showed fair score percentage, and only (6.7%) showed good percentage (Elsakka et al., 2021). The finding in this study shows about (31.1%) of mothers who had witnessed the seizure of their children never put something between their children's jaws meanwhile almost half of parents in another study would put a spoon between the teeth of their children while having a seizure. Moreover, contrast with study in Thailand, shows that more than half of caregivers routinely performed incorrect procedures while patient having seizure including shaking the patient to wake them up and restraining the patient. Most caregivers have a high chance of mismanaging patient when they were in an emergency situation and in giving medication (Saengsuwan et al., 2013). Thus, mother's level of knowledge towards epilepsy had a positive impact on their first -aid behaviours during the last seizure that emphasize the influence of the proper training in epilepsy about the first aid practices (Kolahi et al., 2017). Delay or inappropriate management of acute seizures may have serious hazardous consequences with subsequent brain damages or even death.

5.1 Limitations.

The study had several limitations. We obtained only 135 participants out of 265 due to time constraints and a limited data collection period of three months (January to March 2024). Children with epilepsy only seek treatment on Sundays, as it falls under neurology cases, which reduces the number of respondents per week. Additionally, conducting the study specifically in a paediatric clinic limited the number of respondents. Moreover, poor cooperation from the mothers also limitation in this study. Some mothers also refused to participate because they attended the clinic without their husbands and struggled to manage their children, making it difficult for them to concentrate on the questionnaire thus led to their initial refusal to participate.

6.0 CONCLUSION

In alignment with this study objective, an adopted questionnaire from previous studies by (Kolahi et al., 2017) had been distributed to 135 participants to determine the knowledge, attitude, and practice among mothers with epilepsy children in Hospital Universiti Sains Malaysia. Overall findings of the study revealed that most mothers have good knowledge about epilepsy, with 56.3% demonstrating solid understanding. Additionally, about 20.7% have very good knowledge, 20% have fair knowledge, and only 3.0% of mothers have poor knowledge regarding epilepsy. Besides that, the overall mother’s attitude was neutral which 84.4% is, about 11.1% have negative attitude only 4.4% of them have good attitude regarding epilepsy. Moreover, overall mother’s practice during last seizure was good which is 60.0%, about 37.8% have very good practice and only 2.2% have poor practice. Apart from that, in terms of association between knowledge and selected sociodemographic factors (educational level) toward epilepsy among mothers with epilepsy children, chi square analyses were used. The result revealed that there is no association between knowledge and educational level among mother with epilepsy children in paediatric clinic, Hospital Universiti Sains Malaysia. Thus, the null hypothesis is accepted.

The study findings can be used as baseline data to evaluate the knowledge, attitude, and practice among mothers with epilepsy children which holds significant implications for nursing practice. As nurses are educators, these results will be utilized to assess the needs, deliver information, and evaluate the learning process, especially for mother with epilepsy children. This knowledge allows nurses to provide tailored education and support, ultimately improving the care and quality of life for both the children and their families. Nurses can educate mothers about epilepsy by giving clear, sensitive information about the condition, its management, treatments, and possible complications. They should make sure the materials are easy to understand and available to everyone, no matter their education level. Nurses should also offer counselling and emotional support, helping mothers with any fears or misunderstandings about epilepsy. Nurses can also help mothers find support groups or community resources for extra help.

Implication for nursing education should include information on epilepsy and its management to prepare future nurses to support mothers with children who have epilepsy. Emphasizing communication skills and cultural sensitivity training can help nurses provide better care to families affected by epilepsy. Additionally, hands-on experiences and simulations can help nursing students understand the challenges faced by these families and develop empathy and effective caregiving strategies. Targeted initiatives should also be developed to educate communities about seizure first aid and how to support individuals with epilepsy. Nursing education also can create public awareness and can help dispel myths, reduce stigma surrounding epilepsy ultimately improving the quality of life of the children with epilepsy and their families.

7.0 Recommendation

The data obtained from this study can be used as preliminary data for future research on knowledge, attitudes, and practices among mothers with epilepsy children. The research recommends for future research to include a larger sample size and population to increase general ability of the result. Future research also should focus on understanding how educational interventions can improve the knowledge, attitudes, and practices of mothers with children who have epilepsy. Additionally, exploring the impact of cultural beliefs and community support systems on the care of children with epilepsy would provide valuable insights for developing targeted interventions. Furthermore, investigating the effectiveness of telehealth and online resources in supporting mothers in managing their child's epilepsy could be beneficial, especially in areas with limited access to healthcare services. Unfortunately, not all mothers possess good knowledge about epilepsy, which can hinder effective care and management. There are several strategies to improve the knowledge of mothers with children who have epilepsy including conducting regular educational workshops and seminars at hospitals and community centres can provide mothers with the information they need about epilepsy. These sessions should cover the basics of epilepsy, its symptoms, treatment options, and first aid during seizures. Moreover, providing easy-to-read pamphlets and brochures in clinics and hospitals can give mothers access to important information about epilepsy and arranging home visits to ensure that mothers receive personalized guidance in their own environment. These visits can help monitor the child’s condition and provide on-the-spot education and support.

Conclusion

Concisely, among 135 of mothers’ voluntary responded in this study, about 76 of them had good knowledge, followed by 28 of them had very good knowledge, about 27 of mothers had fair knowledge, and lastly 4 of them had poor knowledge. For attitude among mothers with epilepsy, most of them about 114 mothers had neutral attitude, followed by 15 of them had negative attitude and lastly 6 mothers had positive attitude. Moreover, for practice among mothers with epilepsy child, 81 of them had good practice, followed by 51 of them had very good practice and only 3 of them had poor practice. This research also shown that there is no association between knowledge and selected sociodemographic factors (education level) toward epilepsy among mothers with epilepsy children in paediatric clinic, Hospital Universiti Sains Malaysia where (p > 0.05). Therefore, there is a need for improving the degree of knowledge, which will help in improving their attitudes toward epilepsy to enhance the care and support of their children. It also helps reduce stigma and supports emotional well-being since positive attitudes lead to better management of epilepsy, advocacy for the child, and overall improved quality of life for both the child and the family.

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