Exploring the needs and challenges of parents and their children in childhood epilepsy care: A qualitative study

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A B S T R A C T
Because of the nature of epilepsy, and the unpredictability of seizure recurrence, epilepsy requires long-term treatment with medications. As a consequence, epilepsy has a negative pervasive impact in children with epilepsy (CWE), and their parents. Hence, our aim was to explore the needs and challenges of parents and their CWE. In-depth interviews (IDIs) were conducted with 15 families (12 mothers and 3 fathers) and 15 CWE (aged 8–18 years). Data were transcribed verbatim and thematically analyzed using the descriptive phenomenology approach. The experiences of parents and their CWE could be divided into two time frames: “experiences during a child’s first seizure” and “experiences whilst growing up with epilepsy”. Parents’ main concerns and worries were regarding their child’s physical health, psychological and emotional wellbeing, academic achievement, and future. The child’s main concerns were restrictions imposed, their interpersonal relationship with peers, and being independent in the future. Parents reported that they needed epilepsy-related information, continuity of care, and a parental support group, while CWE reported that their main needs were independence and autonomy. The views of parents and their child with epilepsy were similar in physical functioning and academic achievement. However, parents and children had different views on how epilepsy impacted on the child emotionally, as well as behavioral and interpersonal relationship with peers.

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1. Introduction
During an epileptic seizure, a child may experience sudden loss of consciousness, jerking, injuries, and bowel incontinence [1]. The unpredictability of seizure recurrence requires the child to have long-term treatment with medication that has adverse effects. As a consequence, epilepsy has a negative pervasive impact in children with epilepsy (CWE) and is associated with a poorer health-related quality of life (HRQOL) [2]. Epilepsy has also been found to be associated with poorer academic achievement [3]. Thus, the goal of treatment in patients with epilepsy is to achieve “seizure-free status” and to minimize the adverse effects of medications [4].

Although children bear much of the burden of epilepsy, parents also suffer the negative consequences of caring for a child with epilepsy [1]. Parents experience stress as they are required to make decisions concerning the care and future of their child [1]. Mothers are usually at a high risk for psychological distress, such as depression and anxiety than norms [5,6]. The more depressed the mother is, the higher the negative impact she has on the child’s HRQOL, especially during the first two years after diagnosis [5]. In addition, family functioning [7], parental stress [8], and parents’ anxiety about epilepsy [9] have been found to be negatively associated with a child’s HRQOL. Therefore, parental adjustment is an important area to focus on to improve HRQOL in CWE [10].

Psychosocial and educational interventions can effectively improve psychological and emotional wellbeing in CWE and their parents [11, 12]. By strengthening or reinforcing functional coping, parents can enhance their children’s psychological, social, and emotional development [13]. Parent’s coping capability and psychological wellbeing, which are influenced by culture and social belief, have a significant impact on their child’s HRQOL [14].

Qualitative research is particularly useful in understanding how an individual with epilepsy and their family bring meaning to their experience with epilepsy. Qualitative research also allows researchers to understand epilepsy management, changes in their health over time, and how they perceive care from healthcare providers [15–19]. Several qualitative studies have been conducted to assess the needs and challenges in parents and their CWE in Ireland, Taiwan, French, Sri Lanka, and United States. Studies found that parents’ main concerns include side effects of antiepileptic drugs (AEDs) [20], epilepsy-related information [17,20,21], future of their child with epilepsy [21,22], child’s self-esteem [22], disclosure of epilepsy to others or stigma [18,23], and dealing with healthcare providers [17]. Other studies found that the children’s main concern include restriction of activities [24–26], side effect of medication [24,25,27],

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disclosure of epilepsy [28,29], need for information during doctor consultation [29,30], academic achievement [28,29], emotional problems [28], and interpersonal relationship [27,29].

Malaysia is a multicultural society of which is made up by different ethnic groups (Malays, Chinese, Indian, and the Native). Study also found that there is lack of public awareness toward epilepsy compared with other developed countries [31]. Therefore, the multiracial cultural factor and medical systems in Malaysia may differentially influence parents and their children compared with other areas of the world. To date, there is a paucity of information regarding the needs and challenges of parents and their children in Malaysia. Therefore, the main aim of this study was to explore the experiences of parents and their children, and to identify the needs and challenges faced by parents and children in childhood epilepsy care.

2. Methods

2.1. Participants

Participants were recruited from the pediatric (children aged 8–18 years) and adult neurology (children aged 15–18 years) clinics of a tertiary hospital in Kuala Lumpur, Malaysia from December 2013 to June 2015. Included were parents and their children aged 8–18 years, who have been diagnosed with epilepsy >6 months, have ≤4 seizures in the past 6 months (epilepsy that is under “control”) and attending regular school. These children with controlled seizure may be seen as “normal” compared with other CWE. They may have different needs and challenges in this group of children, which had not been explored in previous studies. Excluded were parents of children with learning difficulties, uncontrolled seizures (>4 seizures in the past 6 months), other chronic illness (e.g., cerebral palsy), and other comorbidities (e.g., attention-deficit hyperactive disorder, autism). Purposive sampling based on the child’s age was used. The CWE were divided into 2 main categories: children aged 8–12 years and adolescents aged 13–17 years, as adolescents may face different challenges from younger children and place more emphasis on peer relationship and independence [32]. Recruitment of participants ceased when thematic saturation occurred.

2.2. Procedure

Ethics approval was obtained from the University Malaya Medical Centre Ethics Committee prior to the study (approval number: 968.21). Parents were approached when they were waiting to see the doctor at the clinic. The purpose of the study was explained, and written inform consent was obtained from those who agreed to participate. Baseline demographic data were collected, and an appointment was given for the in-depth interviews (IDIs) within one week.

The topic guides for parents and children was developed based on literature review and the ABCX model conceptual framework. This model was used to explain how a family would respond to stress, and the strategies needed to improve family functioning [33]. The topic guide was also developed based on the caregiver stress process model. This model explains how caregivers respond to problematic conditions and difficult circumstances due to chronic illness [34]. The topic guide was also developed based on the Erik Erikson’s psychosocial development theory, which describes the social and emotional aspects of health growth in children [32]. Lastly, the topic guide was developed based on the model of children’s attitude toward epilepsy, which explains how family functioning occurs, a child’s worry about seizure, and a child’s self-efficacy for seizure management impact on a child’s attitudes toward epilepsy [35]. The topic guide for parents and children has three parts: impact of epilepsy on the family, support/resources available, and coping strategies (Tables 1 and 2).

All IDIs were conducted with parents and children at their respective homes in their preferred language: English, Malay, Chinese, or Tamil. Interviews were audio recorded, and lasted from 30 to 60 min for parents and 15–30 min for children, respectively. After the interview, initial impressions and thoughts about participants were recorded in a research diary. Any additional information from post-interview conversations was also included as field notes.

2.3. Data analysis

All interviews were transcribed verbatim by experienced transcribers. Data analysis was facilitated by using Nvivo 10 (QSR International Pty. Ltd. Version 10, 2012). Data were analyzed using the descriptive phenomenology approach and thematic analysis in three phases. During the first phase, SWW (one of the researchers) coded each interview line-by-line to develop an initial list of codes (open coding). Subsequent interviews were then coded using this list (a process of constant comparison) and new themes that emerged were added to the list [36]. During the second phase, open codes were organized and reorganized conceptually into broader categories based on thematic similarities between open codes or “axial coding”. Throughout the coding process, codes were checked by researchers to ensure consistency of coding and consensus on axial coding. In the final phase, core categories and subcategories were organized within each conceptual domain and conceptually connected to one another, generating a theoretical representation of relationships among concepts.

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<th>Table 1</th>
<th>Topic guide for parents who have a child with epilepsy.</th>
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<td>Items related to this section</td>
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<tr>
<td>Impact of epilepsy on the family</td>
<td>• How did you feel when your child was first diagnosed with epilepsy?</td>
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<tr>
<td>Support/resources available</td>
<td>• How has epilepsy changed your child?</td>
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<tr>
<td>Coping strategies</td>
<td>• How has epilepsy changed you and your family?</td>
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<td>Coping strategies</td>
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<td>Coping strategies</td>
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<td>Section</td>
<td>Items related to this section</td>
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<td>• How did you feel when you were told that you have epilepsy?</td>
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<tr>
<td>Support/resources available</td>
<td>• What do you understand by the term “epilepsy”?</td>
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<td>Coping strategies</td>
<td>• How has epilepsy changed your life?</td>
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<td>Coping strategies</td>
<td>• What is your ambition? Do you think epilepsy will affect your future?</td>
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<tr>
<td>Coping strategies</td>
<td>• Do you feel stigmatized by your child’s epilepsy?</td>
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<tr>
<td>Coping strategies</td>
<td>• Is the interaction between you and your healthcare professional (e.g., doctor, nurses, counselor, and pharmacist) positive?</td>
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<td>Coping strategies</td>
<td>• Do you think religion helps you cope?</td>
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<td>Coping strategies</td>
<td>• Do you know of any nongovernment organization that can help?</td>
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<td>Coping strategies</td>
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• Do you cope with the challenges which you have just mentioned? |
• Have you participated in any workshop, seminar, or talks that would help you and your child with epilepsy? |
• How else can we supplement your needs to help you cope better? |
• How do you cope with the challenges which you have just mentioned? |
• How else can we supplement your needs to help you cope better? |
3. Results

A total of 15 families were interviewed (18 parents and 15 children), as three interviews involved both parents. The mean age of parents was 42.1 years, SD = 5.6 years (age range: 33–58 years). A total of eight males and seven females were recruited. The children’s mean age was 12.7 years, SD = 1.7 (range: 8–17 years). The mean duration of epilepsy was 5.0, SD = 3.5 years (range: 2–10 years). These children were diagnosed with idiopathic generalized epilepsy \( (n = 8) \), childhood/adolescent absence epilepsy \( (n = 6) \), and focal epilepsy \( (n = 1) \).

The experiences of parents and their children can be divided into two different time frames: “experiences during child’s first seizure” and “experiences while growing up with epilepsy”. The themes and subthemes are summarized in Table 3.

3.1. Experiences during a child’s first seizure

All parents experienced negative emotional reactions when their child first had a seizure. They were upset, shocked, and worried. They thought that their child was going to die. A parent who was an occupational therapist did not think that his child was going to die, but felt sad because he realized that his child might have epilepsy. Some parents also sought for second opinion to prove that their child did not have a seizure.

That was the first time seizure, I don’t know. I thought “What happened?” I thought, she couldn’t breathe! I thought suddenly she just passed out and gone [died] already.

[43 years old, with a 15-year-old daughter with epilepsy]

In some families, some mothers blamed themselves for “causing” their child to have epilepsy. Additionally, there were some families where the in-laws blamed the mother for “causing” the child to have epilepsy. Some families also believed that epilepsy was a “supernatural” disease, caused by bad spirits.

My husband’s family members are all vegetarian. So they blamed me because I am not a vegetarian, and said that I made my son to have epilepsy.

[45 years old, with a 17-year-old son with epilepsy]

Health-seeking behavior is defined as “actions taken by an individual when seeking help to treat one’s health problem” [37]. It can be further described by what facilitates the use of healthcare services, and what influences an individual to behave differently from others.

At this stage, parents did not look for information actively, as they did not know that their child had epilepsy. Their main concern at this point of time was to find out what happened to their child, and to find a “cure” for their child’s seizure. Some parents did not know what to do when their child had a seizure. They followed practices passed on by “old folks” such as putting a spoon inside the child’s mouth during a seizure.

We used a spoon whenever our child had a seizure because we were afraid she would bite her tongue.

[45 years old, with a 12-year-old daughter with epilepsy]

Most parents were aware that their child was sick, and needed some sort of care. Some parents sent their child to a healthcare institution, others sent to traditional healers, while one sought advice from a relative on what to do. In some families, parents disagreed on how the child should be cared for, as they had different health beliefs.

…Initially, we went to a temple (traditional healer). But when the seizure became more and more frequent, I felt that something was wrong. I was so worried! I did not believe that traditional healer that much… Without discussing with my husband, I brought him to a hospital to see a doctor.

[44 years old, with an 11-year-old daughter with epilepsy]

On the child’s first seizure, initial reactions were mainly described by children aged 11 years and above, as younger children did not know that they were having a seizure, or were too young to recall their experiences. They just thought that they were sick, and would get better with medication.

My mother said that I was sick and I have to eat (take) medications. The doctor said two days later I will be fine.

[8-year-old boy with epilepsy]

Fatigue and excessive tiredness was experienced by some children after their first seizure. Some children noted that their tiredness lasted for a couple of hours, while others were tired for the whole day. Some children were conscious, but felt like they were “stuck inside” their body during their seizure. A total of eight children in this study had generalized epilepsy. They reported that they lost consciousness or “went blank” during their seizure; thus, they could not remember anything.

Table 3

<table>
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<th>Time frame</th>
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<td></td>
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<td>• Need for epilepsy-related information</td>
<td>• Need for continuity of care</td>
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<td></td>
<td>• Need for a parental support group</td>
<td>• Impact of epilepsy on the child</td>
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<tr>
<td>Parents’ perceived impact of epilepsy on their child</td>
<td>• Physical changes</td>
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<td></td>
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</tr>
<tr>
<td></td>
<td>• Interpersonal relationship</td>
<td>• Impact of epilepsy on the child</td>
</tr>
</tbody>
</table>

…without medication for that long time, I just kept getting tired. My parents used to be really disappointed.

[27 years old, with a 17-year-old daughter with epilepsy]
during a seizure. In addition, most children felt shocked, upset, and scared during or after their seizure.

I can hear people (during my seizure). But I couldn’t move. My whole body was “stuck”. I could not move anywhere. Only my mind was thinking.

[12-year-old girl with epilepsy]

I was not really afraid but I was shocked… (during my seizure).

[12-year-old girl with epilepsy]

3.2. Experiences while growing up with epilepsy

Epilepsy is usually diagnosed several months after a child has their first seizure. At this stage, parents have gotten over their initial shock and may have found out more information about epilepsy.

3.2.1. Impact of epilepsy on the family

Epilepsy has both positive and negative impact on parents and the family. In some families, family members became more united. However in some families, some parents developed health or mental health issues, and some parents were forced to give up their jobs to take care of their child with epilepsy. All parents agreed that their experiences in handling their child with epilepsy improved over time. However, their fear that their child may have a seizure at any time still persisted, even several years after the diagnosis of epilepsy. Some parents became anxious and depressed, because of the stress in caring for their child with epilepsy. All parents reported that they were constantly worried. They worry about their child’s health, school performance, and future (whether they would be able to live independently and have equal rights for employment).

In Malaysia, children who attend public schools receive free medical treatment in public hospitals. We recruited all our participants from a public hospital. Hence, none of our participants reported any financial difficulties in seeking medical care.

My eldest daughter helps me to take care of her [my daughter] when I am away. They are very close siblings. I think we [family members] are closer too because we try to solve our problems together.

[45 years old, with a 12-year-old daughter with epilepsy]

I become anxious when my child screams. It is because when he gets a seizure attack, he screams… That’s why since then I cannot sleep at night if I hear him screaming… even if he is just playing and screaming with his sibling, I become anxious.

[43 years old, with a 13-year-old son with epilepsy]

I am worried about his future career. I’m worried that he cannot find a job due to his epilepsy. And he would not get equal treatment like others when he works in a company.

[45 years old, with a 17-year-old son with epilepsy]

Meanwhile, most children did not report any significant changes on their family before and after their diagnosis of epilepsy. Some children did not report any significant changes on their relationship with their siblings after their diagnosis of epilepsy. Some children felt that their relationship with their siblings grew closer because of epilepsy.

My parents treat my sister and I the same (after the diagnosis of epilepsy). Not much changes in (family) activities.

[12-year-old girl with epilepsy]

My brothers took care of me when my parents were not free. They can protect me.

[11-year-old girl with epilepsy]

3.2.2. Management of epilepsy care

Parents reported that they were continuously watching out for any possible triggers of a seizure attack. All parents imposed restrictions on their child’s physical and social activities (such as sleepovers or planning for an overseas trip), as they were afraid that their child may have a seizure, and no one would know how to care for their child.

… We make sure that you know she eats properly and rests enough… I realized that no matter how much she wants to achieve, I had to stop her for trying too hard.

[45 years old, with a 12-year-old daughter with epilepsy]

All the children in our study were discouraged from participating in physical and social activities that were away from home. This was because their parents thought that participating in these activities would trigger a seizure, or that no one would know how to help them during a seizure. Some CWE also placed restrictions on themselves in order to avoid triggering a seizure. Generally, the teenagers in our study were unhappy when they were not allowed to go out with their friends. However, their parents allowed their friends to come over to their house. Despite the restrictions imposed, the participants did not think that their parents were overprotective, as they were aware that these restrictions were to keep them safe from any possible injury due to a seizure.

I do not like that my parents do not allow me to hang out with my friends other than home. But I have never argued with them. I have to accept it. It is for my own good.

[17-year-old teenage boy with epilepsy]

The caregiving process involves the care of self and of others under your care [34]. All parents reported that they needed to be strong emotionally and spiritually, so that they would have the strength to take care of their child who has epilepsy. Most parents discussed the value of faith in their lives, and how their belief in God has provided them the strength to care. When they felt that they could not handle a problem, they learned how to “let go”.

I was very sad when my daughter was diagnosed with epilepsy. I cried, I cannot do anything right. I did not know what to do. After I cried… I surrender to God. Let God look after it.

[38 years old, with a 15-year-old son with epilepsy]

Parents coped with their problems using two different coping strategies: problem-focused coping and effective emotional-focused coping. Parents who used problem-focused coping would address the problem that was causing distress, and would seek a solution for it. Alternatively, parents who used effective emotion-focused coping would try to reduce the negative emotions that were associated with the problem, such as thinking positively and seeking for emotional support.

We have to find our own information. We find it from the internet… search for anything related on how to take care of him, and how to overcome it [seizure].

[43 years old, with a 13-year-old son with epilepsy]

I talked to my neighbor when I was upset… Sometimes, she taught me how to handle my son when he has fits… Otherwise, I will call my mother. We talked about anything. Although I did not tell her much about my problem, I feel much better after talking to her.

[45 years old, with an 11-year-old son with epilepsy]

Most children adopted problem solving and effective emotional coping strategies in dealing with challenges in life. Some children sought help from their siblings, while others shared their feeling with their
close friends. Some children ignored their problems, hoping that they would go away.

I sleep when I was upset. I cry too. No one knows. I don’t normally share with my friends. I just keep to myself. After that, I will be fine.

[15-year-old teenage girl with epilepsy]

Disclosing to others that their child had epilepsy was not easy for most parents. This was due to the fear of stigmatization, concern that their child’s future would be affected, and worry that their child would not be treated equally by the school teacher.

Yeah. I don’t want to talk about her epilepsy with her school teacher, like she doesn’t want me to tell her teacher, because I can understand that the teacher might not give her the same opportunity [like other classmates]...

[45 years old, with a 12-year-old daughter with epilepsy]

Some parents were willing to disclose to others that their child had epilepsy. For parents who shared this information with others, they felt that a burden has been “lifted off their shoulders”. These parents received positive responses, help, and social support from others. The disclosure of epilepsy also meant that others (such as school teachers and classmates) could help ensure the safety of the child during a seizure. In addition, it also brought parents in a similar situation together.

I treat him [my son] like a normal person. I feel that some parents who have a child with epilepsy dare not tell others, or discuss with others, as they feel embarrassed. I think when we communicate with others, may be, others might tell you: “Oh! I have an idea, on how to take care of the child better”. After you have communicated with others, may be you can get better information!

[38 years old, with an 8-year-old son with epilepsy]

Some CWE selectively disclosed that they had epilepsy to people whom they trust. They did not want others to treat them differently. Others chose not to disclose the fact that they have epilepsy. The two main barriers identified were stigma and “visibility of epilepsy”. Some CWE reported that they experienced stigmatization. They were isolated socially, and viewed by others as “different”, “weird”, and “contagious”. This is because epilepsy is only visible when a seizure occurs, or when a person is seen in public taking their medications. Therefore, when the child told his peers that he has epilepsy, his peers did not believe that he had epilepsy, as he looked “normal”.

I used to be very close with my cousins until I was diagnosed with epilepsy 3 years ago. They no longer come near me during family functions. I tried to explain what epilepsy is all about and not contagious, but they refused to listen.

[14-year-old teenage girl with epilepsy]

Attitude toward an illness has a significant impact on the psychosocial adjustment of CWE [35]. In our study, most children were of the opinion that they would be seizure-free in the future. Family mastery is defined as “a family working together to help a child to deal with epilepsy by maintaining regular family activities, and taking precautions on any possible situation that may trigger a seizure (restriction of social activity)”. As a result, this decreases the child’s worry about epilepsy, and strengthens the child’s self-efficacy for seizure management. Conversely, some children (especially the females) thought that they would never be seizure-free, and that epilepsy would hinder them in their pursuit of achieving their ambitions.

I do not like being epileptic. I have to take medications… I can’t go out with friends… I can’t imagine my life in the future.

[15-year-old teenage girl with epilepsy]

Self-efficacy in this study is defined as how the child handling their epilepsy. Most children in our study did not actively look for information about epilepsy. Some children tried to find some information on the internet, but did not understand what they read. Knowledge about epilepsy was obtained from their parents. Most children in our study also did not know the name or the dosage of the AEDs that they were taking. They also needed to be constantly reminded to take their medications. However, all the children in our study were aware of the importance of taking their medications to control their seizure, and they take it without complaining.

I searched about epilepsy once on the internet and did not understand it.

[15-year-old teenage girl with epilepsy]

Sometimes I remember to take my medicine but sometimes I don’t. But my mum will remind me to take my medicine.

[15-year-old teenage boy with epilepsy]

3.2.3. Unmet needs

Parents wanted doctors to provide them with sufficient information on how to care for a child with seizure. Doctors rarely focused on this aspect. They merely ordered tests to confirm or exclude the diagnosis of epilepsy, and prescribed medications for the seizure. Although doctors provided more information about epilepsy in subsequent visits, some parents feel that the information provided should be more understandable, and doctors should be more frank about the side effects of AEDs. Parents also wanted the latest information related to epilepsy.

Sometime, I can’t be patient, I search on the internet. Whatever it is, whatever method how to take care of my son. This is because the doctor doesn’t give any detail, you know?

[43 years old, with a 13-year-old son with epilepsy]

The doctor always tells me to be at ease about the side effect of antiepileptic medications! …the doctor should be frank. I know that all medications have side effects. But no one told me what the side effect of Epilim is...

[38 years old, with an 8-year-old son of epilepsy]

As we recruited participants from a public hospital, parents were not given a choice on which doctor they would consult with at each follow-up visit. Hence, there was no continuity of care. Some parents were required to repeat the same information to different doctors about their child’s epilepsy at each visit. They became frustrated and tired.

The doctor has my son’s medical record, right? He does not need to ask the same thing again. But every time when he goes for a follow up, or is admitted to the hospital, the doctor would ask: how my son got a seizure, what was his symptoms… I think the doctor does not need to ask again because there is a record! [Raising her voice]

[43 years old, with a 13-year-old son with epilepsy]

Some parents were aware of the importance of a parental support group. They wished to be informed about the availability of an existing epilepsy caregiver support group, hoping to share and exchange information with other parents whose child has epilepsy.

Because even if the doctor wants (to give more information about epilepsy), other patients are waiting outside… He is rushing… So, I am not satisfied. That’s why, we should at least have a community… so that all parents can share their problems… I don’t have anyone to share my
problem with. My husband said it is fine to have a seizure. But what is
the way to solve it? How to share?
[43 years old, with a 13-year-old son with epilepsy]

Meanwhile, most adolescents in our study reported that they
wanted to make their own decisions about their life: such as driving,
what they want to be in the future, and whether to attend the national
service course. One adolescent wished that the doctor would communi-
cate directly with her and involved her if a decision needed to be made
regarding her epilepsy care.

I think I am a better person to answer doctor's question during follow-
up, instead of just asking my mother. I hope the doctor can talk to me
directly in person.
[14-year-old teenage girl with epilepsy]

Most children in the study hoped that they would be seizure-free in
the future. They would like to be independent and fulfill their dreams.
However, some adolescents thought that epilepsy would affect them in
what they can study, which would then subsequently affect their career.

I want to be a policeman after I graduate... I can do it if I work hard.
[16-year-old teenage boy with epilepsy]

3.2.4. Impact of epilepsy on children

Most parents and children did not report any significant physical,
emotional, and behavioral changes before and after their child had a diag-
nosis of epilepsy. However, there was one parent who reported that her
child experienced significant hair and weight loss because of the AED.

I wasn't sure why this happened to her. She has significant hair loss and
became so thin. So the doctor decreased her dosage.
[54-year-old, with a 12-year-old daughter with epilepsy]

I am losing my hair lately. My mum said I am getting thinner than thinner.
So I went to see doctor and doctor said have to cut down my med-
icine (dosage).
[12-year-old girl with epilepsy]

I feel upset whenever I think of my health. I cannot do things that I really
wanted to do.
[15-year-old teenage girl with epilepsy]

In term of school performance, some parents reported no changes in
their child before and after the diagnosis of epilepsy. Other parents re-
ported that epilepsy had a negative impact on their child's school per-
fomance, as they missed school or examinations rather frequently, or they
had problems with understanding what was taught in school. One parent
mentioned that his child's academic achievement improved since taking
AEDs. As a result he was able to concentrate in school, and do well in
his studies. All CWE attended school and were able to participate in school
activities.

...After my daughter was diagnosed with epilepsy, she became so for-
getful. Sometimes she said she cannot understand what the teacher is
talking about in class...
[32 years old, with a 12-year-old daughter with epilepsy]

Before he was diagnosed with epilepsy, he did very badly in school... We
thought he was a slow learner. Until he was diagnosed with epilepsy and
started taking medications, he became better in learning... I think the
medications helped him concentrate better.
[44 years old, with a 17-year-old son with epilepsy]

Some children reported that there was negative impact on their ac-
ademic achievement. Seizure can occur during or after school hours.

Some children had a seizure during school resulting loss of conscious-
ness. They experienced difficulties in concentrating on what was being
taught in class. Some children had a seizure after school hours — e.g.,
during sleep. Hence, they were absent from school the following day.
Other children thought that epilepsy did not have any significant impact
on their academic achievement. Two children reported better academic
achievement in school.

Epilepsy motivated to do better in my study. I put extra effort in my
study because I do not want epilepsy to slow me down.
[17-year-old teenage boy with epilepsy]

In term of interpersonal relationship, most parents thought that
their child had no problems making friends. However, some parents re-
ported that their child did not have any friends in school. They were
peased, "called names", and were bullied in school. Some CWE had se-
ever close friends in school. They received constant emotional and social
support from their close friends whereas others did not want to make
friends, and would rather be alone, or just hang out with one or two
close friends that they could trust. A few children were bullied and iso-
lated socially.

I had a seizure attack in school once. Since then, all my classmates like to
tease me and call me awful names. So now... I do not have any friends
in school.
[12-year-old girl with epilepsy]

4. Discussion

The experiences of parents and their CWE could be divided into two
different time frames: "experiences during a child's first seizure" and
"experiences while growing up with epilepsy". Parents' main concerns
and worries were regarding their child's physical health, psychological
and emotional wellbeing, academic achievement, and future. The
children's main concerns were restrictions imposed, their interpersonal
relationship with peers, and being independent in the future. Parents
reported that they needed epilepsy-related information, continuity of
care, and a parental support group, while CWE reported that their
main needs were independence and autonomy.

Parents' reactions on children's first seizures were consistent with
previous studies and across cultures [23,39–41]. Parents' reaction can
be explained by the five stages of grief model by Kübler-Ross [42]. The
five stages of grief model can be applied to how parents accept a chronic
illness in their child [43]. The first stage is denial, where parents refused
to admit that their child has epilepsy. In this stage, parents may not
comply with medical treatment but seek alternative medicine. The sec-
ond stage is anger. Anger is an emotional act in which parents blame
themselves for causing their child to have seizure. The third stage is
bargaining. It is a negotiative process where parents try to postpone or
distance themselves from the real situation. They may refuse treatment
and find ways to prove that their child does not have a seizure. The next
stage is depression. Soon after the child has more seizures, parents start
to feel that they have lost control. They feel depressed and sad. Depres-
sion may affect sleeping or eating patterns. The final stage is acceptance.
After progressing through the four stages, parents start accepting the
fact that they have a child with epilepsy.

Our findings were similar to a previous study, where an African-
American parent felt guilty that she "allowed" a parasitic infection to
cause the onset of her child's epilepsy [44]. When a mother cannot pro-
tect their child from harm, maternal guilt may occur. Maternal guilt oc-
curs when mothers think that they must fully devote themselves to
their children and feel completely responsible for how their children de-
velop [45]. Mothers who believed they could not live up to either their
own or social expectations for being a perfect mother to their children
were more prone to develop guilt and shame [46,47]. To overcome
this, healthcare providers should educate mothers regarding epilepsy
as a disease, so that they should not blame themselves for “causing” epilepsy to their child. If a parent feels guilty, they should talk to someone about their concerns.

The ABCX-family adaptation model proposes that when a stressor occurs, the family’s existing resources interact to influence family coping behaviors. These coping behaviors will then influence how the family deals with stressors. We found that sociocultural factors influence how parents deal with their child with epilepsy. For example, some parents believed that epilepsy (stressors) was caused by “bad spirits” (sociocultural factor) [48]. Cultural practices and beliefs play a significant role in health-seeking behavior [49]. If one believes that epilepsy is caused by the possession of “bad spirits”, then parents may seek help (coping) from traditional healers (adjustment) rather than from medical doctors [50–52]. It is also common in Thailand [53], China [49], and Zambia [54]. Although the majority of participants believed that modern medicine was still the best treatment for epilepsy, traditional healers still played a salient role [31,50], especially when modern medicine is unable to cure the disease, or when there is no improvement to the condition [50,55]. In addition, some Chinese in Malaysia prefer traditional Chinese herbs for healing epilepsy [56]. This is in contrast to western countries, where belief that epilepsy is caused by supernatural causes is less common [55]. Therefore, providing education to the public to seek health from medical institutions is important. The greater the knowledge and awareness regarding epilepsy, and the effectiveness of the treatment of epilepsy would reduce treatment gap between developed and developing countries [57].

A family with strong family mastery provides positive support to help the parents and their child to deal with their epilepsy [35]. Some family members grew closer by working together to solve problems. Parents showed their love for their child by sacrificing their time, sleep, and job to look after their child. They also became more vigilant in caring for their child who has epilepsy. During this process, parents had to reframe their role as a parent by lowering their expectations on their child’s achievement. The reframing of parental roles is a function of protecting their child and promoting their child’s development [66]. Our findings were similar to previous literature [18,39,40]. Our findings were similar to a previous study where the positive impact on the family included becoming an “expert about epilepsy” and how to manage a child with epilepsy, giving more love and advocacy for their child with epilepsy, as well as recognizing the need to move on over time and live a healthier life [40]. Older siblings would help to take care of their younger sibling who had epilepsy. Our findings concurred with a previous study where siblings accepting their brother or sister with epilepsy for whom they are: “a strong family is about there for one another and getting through what life throws to you...” [58].

As postulated by the model of children’s attitudes toward their epilepsy [35], a child’s attitude toward their epilepsy is governed by family mastery, a child’s worry about epilepsy, and a child’s self-efficacy for seizure management. Most of the CWE were not worried about their epilepsy, and believed that they would be seizure-free in the future. This includes maintaining regular family activities (such as outings and family gatherings), and restriction in social activities that may trigger a seizure. As a result, this decreases the child’s worry about epilepsy and strengthens the child’s self-efficacy for seizure management.

Conversely, some parents reported that epilepsy had sleeping problems and high blood pressure due to the stress of taking care of their child with epilepsy. These findings were consistent with previous studies [40]. Parents who perceived a higher epilepsy severity reported lower sleep quality, lower marital satisfaction, and lower maternal health [59]. Some parents also experienced depression and anxiety, which persisted even a few years after their child had a diagnosis with epilepsy. Similarly, others also reported that their negative emotions had affected their child negatively [44,63]. High levels of parental stress were found to be significantly associated with CWE behavioral problems: internalizing (e.g., anxiety, social withdrawal, and somatic complaints) and externalizing problems (e.g., aggression, bullying, and hyperactivity) [64]. Meanwhile, some of the females in our study also reported more worries and negative attitude toward epilepsy. They reported that they were worried about how epilepsy would affect their future. Our result was similar to a previous study [10]. This maybe because females use more emotional coping and tend to worry more compared to males [65].

The children in this study were passive in seeking for information about epilepsy by themselves. They were contented to leave their parents to seek for information regarding epilepsy. Some studies reported similar findings [69], while other study reported otherwise [17,29,70]. One possible explanation is that these children did not know how to ask questions or they were not given a chance to ask questions. Another explanation is that there was no age appropriate epilepsy information material (e.g., brochure) for these children. Hence, these children lost interest in seeking for epilepsy-related knowledge. This is important to encourage CWE to be active in obtaining information because knowledge regarding epilepsy helps them understand the disease and treatment, and become independent in self-care in the future [71].

Both parents and children coped using two coping strategies, problem-focused coping and emotional-focused coping. Parents who used problem-focused coping would address the problem that was causing distress, and would seek a solution for it. Parents who used emotion-focused coping would try to reduce the negative emotions that were associated with the problem, such as praying, thinking positively, and seeking for emotional support. This was consistent with the ABCX model [33]. Emotion-focused coping attempts to avoid or counteract negative emotions associated with the stressor, while problem-focused coping is an active attempt to solve the problem directly related to the source of stress [72].

The majority of parents and children in this study decided to conceal (not disclose their child’s epilepsy), or selectively (disclose to close people such as close friends, extended family, school teacher, or neighbors) the fact that their child has epilepsy. Only a few parents decided to voluntary disclose (openly discuss about their child’s epilepsy to others) this fact to others. The barriers to disclosure of epilepsy were similar to previous studies, which were fear of stigmatization [73], fear to be treated differently in school, and concern that future would be affected by stigmatization [15,18]. Although concealment or selective disclosure may protect their child/themselves from epilepsy-related stigma [74], one study found that individuals who concealed their medical condition had poorer psychosocial outcomes [75]. This was because such silence may reinforce misunderstanding about epilepsy, and increase stigmatization. In addition, concealment and selective disclosure can increase the risk of physical harm to the child with epilepsy, as other people around the child may not know what to do during a seizure. The facilitators for disclosure in our study were similar to previous studies: disclosure to family members or teacher to ensure the child’s safety when away from home, and encouraging reactions by others when parents discuss about epilepsy [76,77].

All of the parents in our study reported that they needed more updated epilepsy-related information, which was similar with a previous study [17]. Parents also felt lack of continuity of care, which prevented child from receiving optimal care [78]. Continuity of care has been found to be beneficial as an ongoing doctor–patient relationship builds over time because this can then lead to more in-depth discussions, about important issues, between parents and their usual doctor [79]. In addition, parents needed of a social support group from other parents to share common experience between parents, and help to cope with difficult situations by sharing personal experiences and feedback [80–83].

The children in this study were more concerned about gaining independence and wanting autonomy. Some children reported that they were worried when they thought about how epilepsy would affect their live in the future. For example, they were worried as to whether they were able to become independent (e.g., employment). Our findings were similar to a previous finding [27], consistent with Erik
Erikson’s psychosocial development theory [32] growing children’s need for independence and autonomy. Our study explored both the parents and child’s view. To date, only one qualitative study explored the concerns and needs of parents and their CWE [17], but did not compare their views.

Previous studies showed that there was a high level of agreement between parent proxy and child self-report ratings on external life experiences, such as the physical and social wellbeing of the child; where the parent was able to observe the conduct of their child. However, parents were not able to accurately report their child’s internal experience (such as their attitude toward epilepsy) [84]. Our findings concurred with previous studies where the views of parents and their child with epilepsy were similar in the following areas: physical functioning [85], academic achievement [27,29], and bullying [86].

The areas where the parent’s and child’s view differed were as follows: emotional functioning, behavioral changes, and interpersonal relationship. Parents reported that their child with epilepsy gets angry easily. However, none of the children in our study reported that they angered easily. Instead, the children reported that they were frustrated and upset because of the restrictions imposed by their parents. When a child does not know how to express their frustration, they may react by being angry, as perceived by their parents. There was no prior literature to compare our findings.

Most parents and CWE did not report any significant behavior changes due to epilepsy. Our findings contradicted with published literature, which reported that CWE displayed more behavioral problems [87]. This may be because previous studies reported behavioral problem that were observed and rated by their parents [88] and teachers [89]. The children did not rate themselves in term of behavioral problems. Children may not understand the implications of their own behavior. They may not be aware that their behavior was “problematic”. Secondly, behavioral problems in a child (such as screaming and throwing tantrums) may be a way of expression for the child who lacks of the social or language skills [90].

Our study also found a disagreement between parent’s and child’s view on interpersonal relationship. This finding was consistent with a previous study, which reported that there was low agreement between mothers and children in peer relationships [91]. Most parents thought that their child had no problems making friends and have many friends. However, CWE in this study reported that they did not want to make friends, and would rather be alone, or just hang out with one or two close friends that they could trust.

The strength of this study was that the views of both parents and children were explored and were compared. One of the limitations of this study was that we recruited parents and their children with controlled seizures. Therefore, findings from this study may not be applicable to other CWE whose seizures are not well-controlled. Besides, there were imbalance of gender, ethnicity, and Socioeconomic status (SES). Therefore, our participants were not representative of the Malaysian population.

5. Conclusions

One unique finding from our qualitative study was the health-seeking behavior among parents of CWE. When parents believed that epilepsy was caused by “bad spirits”, they sought treatment from traditional healers rather than from medical doctors. The study also found that some parents in Malaysia reported that they were less likely to talk about epilepsy openly with their child, and hence, influence their child’s attitude toward epilepsy. Therefore, psychosocial interventions that improve knowledge related to epilepsy, support, and encourage healthy parent–child relationships and self-esteem can help to increase their children’s HRQOL. On the other hand, children in this study reported tiredness after a seizure and side effects of AED have affected their academic achievement. Therefore, educational intervention can be developed to help CWE to cope with their school performance.

Parents, healthcare providers, and school teachers should collaborate closely to understand CWE learning in school (e.g., monitor how AED can affect their child’s learning).

Conflict of interest

All authors declare that they have no conflict of interest.

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