



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

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ABSTRACT

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 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. 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 CWE 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 informed 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

Table 1
Topic guide for parents who have a child with epilepsy.

Section	Items related to this section
Impact of epilepsy on the family	<ul style="list-style-type: none"> • How did you feel when your child was first diagnosed with epilepsy? • How has epilepsy changed your child? • How has epilepsy changed you and your family? • What challenges do you have in taking care of your child? • Are there any restrictions that affect your family? What are these restrictions? • What do you think about your child’s future?
Support/resources available	<ul style="list-style-type: none"> • Do you have any form of social support? • Do you feel stigmatized by your child’s epilepsy? • How is the interaction between you and your healthcare professional (e.g., doctor, nurses, counselor, and pharmacist)? • Do you think religion helps you cope? • Do you know of any nongovernment organization that can help? • How is your financial status?
Coping strategies	<ul style="list-style-type: none"> • How 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?

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.

Table 2
Topic guide for children with epilepsy.

Section	Items related to this section
Impact of epilepsy on the family	<ul style="list-style-type: none"> • How did you feel when you were told that you have epilepsy? • What do you understand by the term “epilepsy”? • How has epilepsy changed your life? • What is your ambition? Do you think epilepsy will affect your future?
Support/resources available	<ul style="list-style-type: none"> • Who cares and helps you the most when you are sick (epilepsy)? • Who do you talk to or share your feelings with when you are sick (epilepsy)? • Did you tell anyone that you have epilepsy? • How did others react when you told them you had epilepsy? How did that make you feel?
Coping strategies	<ul style="list-style-type: none"> • How do you cope with the challenges which you have just mentioned? • Do you want others to help you cope with epilepsy? How?

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