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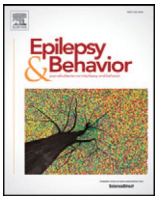

Provision of sudden unexpected death in epilepsy (SUDEP) information among Malaysian parents of children with epilepsy

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ABSTRACT

Sudden unexpected death in epilepsy (SUDEP) is an important cause of mortality in epilepsy. To date, there is only one published UK study evaluating information provision of SUDEP among parents of children with epilepsy (CWE), and there are no studies published from Asia. Although SUDEP information provision is recommended among parents of CWE, it is uncertain if these recommendations are applicable to Asian countries due to the different cultural attitude towards epilepsy. Our prospective cohort study consisted of multiethnic parents of children with epilepsy (CWE) seen in a tertiary hospital in Malaysia. Information on SUDEP was delivered to parents using an epilepsy educational software program. Participants completed a set of standardized questionnaire and Depression Anxiety Stress Scales–Short Form (DASS-21) immediately after and retested 3–6 months after the SUDEP information provision. A total of 127 parents (84 mothers) participated in the study. The CWE consisted of 3 ethnic groups (38% Malay, 30% Chinese, 32% Indian) with a mean age of 9.6 years. Majority (70.9%) felt positive after SUDEP information provision, 90.6% wanted SUDEP discussion for themselves with 70.1% wanted SUDEP discussion with their child, and a lower proportion (58.3%) would discuss SUDEP with their child. None of the participants reported increased symptoms of depression, stress or anxiety attributed to SUDEP information provision. Most parents took steps to reduce SUDEP risk, and most parents did not report an impact on their own functioning. However, there was an increase in parental report over time of impact on their child's functioning following SUDEP information ($P < 0.05$). In conclusion, most Malaysian parents of CWE wanted SUDEP information. Following SUDEP information disclosure, majority did not report negative emotions; however, an increase in parents over time reported an impact on their child. Our findings reiterate that provision of SUDEP information should form part of care of CWE and parents should receive ongoing support as they undergo a period of parenting adjustment when dealing with the information provided.

1. Introduction

Epilepsy is a neurological disorder characterized by an enduring predisposition to recurrent seizures associated with risks of accidental injury and sudden death [1]. Sudden unexpected death in epilepsy (SUDEP) is defined as the sudden, unexpected, witnessed or unwitnessed, nontraumatic, and nondrowning death in patients with epilepsy, with or without evidence for a seizure, with exclusion of documented status epilepticus, and when postmortem examination does not reveal a structural or toxicological cause for death [2]. It is a significant cause of mortality with a systematic review in 2014 reporting that SUDEP contributed an estimated overall crude annual incidence rate of 1.16 cases per 1000 patients, which was only second to stroke in terms of mortality burden from neurological diseases [3]. The National Institute for Health and Clinical Excellence (NICE) in the United Kingdom and the American Epilepsy Society recommend that tailored information and discussion between the child with epilepsy, their family and the healthcare professionals should include the small but definite risk of SUDEP [4,5]. Nonetheless, this recommendation is not adopted universally by the healthcare profession [6–8].

Studies done in the Western countries showed the majority of parents of children with epilepsy (CWE) want SUDEP counseling at the time of diagnosis of epilepsy [9,10]. However, Asian countries differ from Western countries due to different cultural attitude towards epilepsy [11]. These cross-cultural differences may extend to beliefs of SUDEP and attitudes towards SUDEP counseling. It is uncertain if SUDEP information provision is acceptable to Asian parents and whether they would conceal this information from their child. To date, no SUDEP studies have been conducted in Asian countries; hence, the awareness of SUDEP and the potential effects of provision of SUDEP information on Asian parents are unknown. In Malaysia, pediatric neurologists do not routinely provide SUDEP counseling to parents of

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CWE. In addition, the multiethnic makeup of the Malaysian population may present unique challenges in the timing and method of delivery of the information on SUDEP.

Hence, the objectives of this study were to: i) explore the beliefs of Malaysian parents of CWE following the provision of information on SUDEP; ii) evaluate the effects following SUDEP disclosure on the parent's function, parenting, and also the child's function, and if these effects remained stable over time; and iii) determine if there were any epilepsy or parental characteristics that were associated with a willingness to be provided with information on SUDEP. Findings from this research could potentially assist in tailoring guidelines for providing information on SUDEP among Asian parents.

2. Method

2.1. Patient recruitment

This study was a prospective repeated-measures design and conducted on all parents/guardians of CWE aged up to 18 years old who attended the University Malaya Medical Centre (UMMC) Kuala Lumpur pediatric neurology clinic between 1 June 2014 and 31 May 2015. Participants were recruited in the study if their child had an established diagnosis of epilepsy. Information on SUDEP was delivered as part of an epilepsy educational program to the parents using the validated Interactive Epilepsy Education Programme (IAEEP), an epilepsy educational software program developed by the Institute for Community Development and Quality of Life, University Sultan Zainal Abidin, Malaysia, that was further revised by the Division of Paediatric Neurology, University Malaya [12]. The IAEEP software program gave participants clear and concise information regarding SUDEP. Prior to the study, clinicians in UMMC would not routinely discuss SUDEP with families of CWE. Ethical approval was obtained from the UMMC Medical Research and Ethics Committee (Ref: 24145–278). Parents/guardians of all patients eligible for the study were given a verbal explanation of the study and provided with a patient information sheet. Written consent was obtained from all participants.

2.2. Data collection

Clinical data were obtained using a standard proforma sheet, which included the following:

(1) Demographic data: age, sex, ethnicity, total monthly household income, parental education level.
(2) Epilepsy history including potential known risk factors for SUDEP: seizure type, seizure frequency, epilepsy duration, antiepileptic drug treatment, ongoing nocturnal seizures, and history of status epilepticus.

The participants answered a set of standardized questionnaires at two different time points; immediately after [Time Point 1 (TP1)] and 3–6 months [Time Point 2 (TP2)] after the SUDEP information provision. Participants were given two phone reminders to attend the clinic at TP2. The questionnaires used include the following:

(1) Prior to the SUDEP information provision, participants completed the DASS-21 (Depression Anxiety Stress Scales–Short Form) questionnaire which is a self-report scale to measure emotional distress [13] that has been validated in the Malay language [14]. There are 21 items that yield three scales: depression, anxiety, and stress. All answers are based on a 4-point Likert scale (0 = never; 1 = sometimes; 2 = often; 3 = almost always), with higher scores indicating a more negative state of mind. Participants who had scores indicating severe or extremely severe level of depression, anxiety, or stress were interviewed by the clinician to determine if they would still consent to participate in the study. At TP2, this procedure was repeated after participants had again completed the DASS-21 questionnaire.
(2) Immediately after the SUDEP information provision at TP1, participants completed a questionnaire to assess their awareness and beliefs of SUDEP; and the effects of SUDEP information provision on them. The questionnaire used was similar to a SUDEP questionnaire previously reported which used a structured format with closed/fixed alternative and scaled items (Supplement Table 1) [9]. The questionnaire was piloted among 25 Malaysian parents of CWE. All the pilot participants considered the questionnaire fully understandable to them and all the responses were noted to be consistent. The following aspects were assessed: prior awareness on SUDEP, parental/guardian feelings towards SUDEP information provision, whether SUDEP information should be disclosed to them and their child, whether they plan to inform their child about SUDEP, preference to receive SUDEP information, beliefs regarding impact of SUDEP information provision on themselves, and the way they would parent their child. The same questionnaire was used at TP2 to assess the stability of the effects of SUDEP information provision over time.

2.3. Statistical analysis

The sample size required was performed based on the previous study showing that 91% of parents wanted to know about SUDEP [9]. The sample size required (with 0.1 confidence interval width and 95% confidence interval) is 125 patients.

The data were analyzed using the statistical software SPSS 17.0 to generate descriptive statistics. The chi-square test (or Fisher's exact test for cell values <5) was used to explore the relationship between categorical variables while the Wilcoxon signed rank test was employed to determine the significance of the differences observed between the two different time points. A P-value of <0.05 was considered statistically significant.

3. Results

3.1. Patient characteristics

A total of 142 parents/guardians of CWE were initially recruited at TP1. Fifteen participants did not return at TP2 with the remainder 127 participants (89.4%) successfully completed the questionnaires at both time points (TP1 and TP2) and were finally included in our study. Of the 127 participants, 42 (33.1%) were fathers, 84 (66.1%) were mothers and one participant was a female guardian. The mean age of the CWE was 9.6 years (standard deviation 4.7 years), and 75 (59.1%) were males. The CWE were of three different ethnic groups: 48 Malays (37.8%), 38 Chinese (29.9%) and 41 Indians (32.3%). Most (96 of 127, 75.6%) of the CWE had no comorbidities, while 31 (24.4%) had one of the following comorbidities: physical disability ($n = 7$), learning difficulty ($n = 18$), or other comorbidities ($n = 6$). Highest education received by both the fathers and mothers of CWE showed similar distributions [fathers' education level: primary (2.4%), secondary (63.8%), tertiary (33.8%); mothers' education level: primary (3.9%), secondary (65.4%), tertiary (30.7%)]. The basic characteristics of the participants are shown in Table 1.

3.2. Epilepsy characteristics

Seizure types of the CWE were classified into generalized and focal seizure according to the International League Against Epilepsy (ILAE) Commission on Classification and Terminology [15]. In our study, 51 (40.1%) of CWE had generalized seizure of which 45 (35.4%) patients had generalized tonic–clonic seizure and 76 (59.9%) had focal seizure.