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Parent and caregiver knowledge, beliefs, and responses to convulsive seizures in children in Kingston, Jamaica — A hospital-based survey

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ABSTRACT

Objective: The objective of this study was to determine the knowledge and beliefs about seizures and actions during seizures of parents/caregivers of Jamaican children hospitalized for convulsive seizures.
Design and methods: This was a cross-sectional study of parents and caregivers of children with acute convulsive seizures hospitalized at the Bustamante Hospital, Kingston, Jamaica between May 1 and October 31, 2013. Subjects were identified by admission records. Parents/caregivers were invited to participate. A questionnaire on the demographics, knowledge, beliefs, and response of parents/caregivers during the child's current seizure episode was administered face to face. Data were analyzed for frequencies: groups were compared using chi-square analysis for categorical variables, Student's t-test for normally distributed data, and the Mann–Whitney U-test for data not normally distributed.
Results: There were fifty participants: 39 (78%) mothers, mean (SD) age — 33.8 (10.1) years. All sought medical care first. Twenty-two (44%) had plausible beliefs about the cause of seizures. Twenty-seven (54%) knew of appropriate actions during a seizure, 10 (20%) knew of appropriate precautions, and 11 (22%) responded appropriately during the seizure. Eleven (22%) reported receiving seizure education. Witnessing a previous seizure, education level, and seizure education were associated with knowledge of seizures ($p < 0.05$). Socioeconomic status was higher in those with plausible beliefs about seizures and lower in those who took appropriate action during a seizure ($p < 0.05$).
Conclusion: Parents/caregivers of children with convulsive seizures have appropriate health-care seeking behavior, but most do not have appropriate knowledge about seizures. Few take appropriate action during the episode. A public education program is needed to improve parental knowledge of and response to convulsive seizures.

1. Introduction

Parental and caregiver knowledge and response to seizures have been studied in various populations [1–13]. Most studies have been conducted in developing nations of Africa and Asia, and many focus on parental knowledge and response to febrile seizures. In general, parental knowledge has been found to be inadequate, and a frequent response to convulsions is of extreme anxiety and fear that the child will die [4,8,13]. Myths regarding seizures have been documented from a number of countries [2,14]. In Jamaica, myths related to the treatment of individuals experiencing seizures include covering the nose of the victim with an old shoe or rubbing the skin of the victim with thyme, scallion, or alcohol [15]. Inappropriate responses to seizures have also been documented to be prevalent in studies from India [7], Malaysia [13], and Iran [8].

Parental beliefs may influence health-care seeking behavior [16]. Andersen's sociobehavioral model suggests that health-care seeking behavior is affected by many factors — health-care system factors (e.g., distance to health facilities); predisposing factors (e.g., health beliefs); enabling factors (e.g., transportation); and need, which refers to the severity of the illness and whether people judge their illness to be of sufficient magnitude to consult health services [16]. In Kenya, failure to seek biomedical treatment was associated with patients holding traditional religious beliefs, having negative attitudes about biomedical treatment, living more than 30 km from health facilities, paying for antiepileptic drugs (AEDs), and having learning difficulties [17]. In the US, among African-Americans with epilepsy, four major obstacles to care were found. These were limited financial resources, lack of knowledge about epilepsy, poor patient–provider communication, and lack of social support which impeded purchasing of medication, adherence to medical treatment, and needed transportation [18]. The appropriate treatment of seizures and epilepsy is, therefore, influenced by cultural beliefs, knowledge, attitudes, and access to care.

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Jamaica is a middle income developing country in the Caribbean with a population of 2.7 million [19]. The island has 24 public hospitals, a regional teaching hospital, and over 330 health centers [20]. The prevalence of febrile seizures in Jamaican children age 2 to 9 years has been estimated to be 10.9 per 1000, and the prevalence of epilepsy has been estimated to be 5.8 per 1000 [21]. Parental and caregiver knowledge and response to convulsive seizures have not been documented from Jamaica. This study was conducted to document the knowledge, beliefs, practices, and health-care seeking behavior of Jamaican parents and caregivers of children with convulsive seizures attending the island's only pediatric hospital and to identify factors that affect health-care seeking behavior. Identification of deficiencies in knowledge and first aid responses as well as parent and caregiver beliefs will determine the educational interventions that may be needed to improve parent and caregiver responses to convulsive seizures.

2. Materials and methods

This was an exploratory cross-sectional study conducted at the Bustamante Hospital for Children (BHC), a 283-bed public hospital, located in Kingston, the capital city of Jamaica. This hospital is the only specialist pediatric hospital in Jamaica and the English-speaking Caribbean. The study was undertaken during the period from May 27 to October 15, 2013. All parents and caregivers of children 1 month to 12 years old admitted to the medical wards at the Bustamante Hospital for Children and diagnosed with febrile or afebrile convulsive seizures during the study period were invited to participate. Children with syncopal episodes or nonconvulsive seizures were excluded.

Parents and caregivers were identified by reviewing the admission register of the pediatric medical wards daily for patients admitted with a diagnosis of seizures. An introductory leaflet was given to the parents/caregivers by the medical doctors working on the ward. The researcher then met with the parent/caregiver at a scheduled time and invited him/her to participate in the study. The semistructured questionnaire was administered by the researcher (DH-P) during a face-to-face interview with the parent/caregiver in a private room of the hospital. This was done not earlier than 12 h and not later than 72 h after admission. The lower limit of 12 h was chosen to allow sufficient time for the parent or caregiver to recover adequately from any emotional stress caused by the seizure event. The upper limit was chosen to ensure accurate recall of the events leading up to the convulsive seizure and to limit the impact of information that caregivers may have acquired from other parents and caregivers in an open ward setting. The average time taken to administer each questionnaire was 15 min. Prior to the interview, informed consent was obtained by the researcher.

2.1. Sample size calculation

A post hoc calculation was done based on an estimate of the prevalence of the main finding from this study that 30% of participants took an appropriate action during the seizure. The required sample size was calculated to be 43.

2.2. Definitions

1. Convulsive seizure: a seizure with tonic, clonic, or tonic–clonic motor activity, described as stiffening, jerking (shaking), or stiffening and jerking respectively.
2. Caregiver: an adult with whom the child lives and who is also responsible for the welfare/needs of that child, and has been so for a period of a year or more.
3. Appropriate measures during the seizure episode — placing the child on his/her side.
4. Plausible causes of seizures — brain pathology, fever, family illness, and flu (in the case of seizures with fever).
5. Occult causes of seizures — demons, bad spirits, and obeah.

2.3. Parent or caregiver interview

The parent/main caregiver was interviewed in a private room of the hospital to obtain information on demographics, the current seizure episode, the parent/caregiver's emotional response to the seizure episode, actions taken during the episode, their health-seeking behavior, and the parent/caregiver's knowledge and beliefs. The questionnaire also included items on household possessions. A socioeconomic status score was calculated by factor analysis using the number of household possessions out of a maximum of 16, crowding (number of persons per habitable room), and sanitation (type of toilet facility and water supply).

Ethical approval to conduct this study was received from the Ethics Committees of the UWI/UHWI and the South East Regional Health Authority (SERHA) of the Ministry of Health, Jamaica.

2.4. Statistical analysis

Descriptive analyses were performed using the Statistical Package for Social Sciences (SPSS) version 19. Student's t-test was used to determine significant differences in the means for data that were normally distributed and the Mann–Whitney U-test for data that were not normally distributed. Chi-square analysis was performed to determine whether there were significant associations between categorical variables. Statistical significance was taken at a p value of <0.05.

3. Results

3.1. Demographics of respondents

Seventy-one parents and caregivers were eligible to participate; 50 were enrolled. Ten declined participation, and in 11, an interview was not possible within 72 h of admission or prior to the child's discharge. The demographic characteristics of these children were similar to study participants (Table 1).

Thirty-nine (78%) participants were mothers of the children with seizures (Table 2). Nine (18%) participants were male; all were fathers. The mean (SD) age of participants was 33.8 (10.1) years. Fifty-six percent were educated to at least the 11th grade of secondary school, and 10 (20%) were educated to the tertiary level. Thirty (60%) were employed: 9 (18%) were highly skilled, 13 (26%) were skilled, 3 (6%) were semiskilled, and 5 (10%) were unskilled. The mean (SD) age of the children was 4.6 (3.1) years. The median number of seizure episodes experienced per child was 4. Twenty-two (44%) children experienced seizures associated with fever (Table 2). Thirty-four (68%) children were male.

3.2. Participant response and action during the current seizure episode

3.2.1. Participant response during the seizure episode

Forty-four (88%) participants were witness to the current seizure episode. When asked to describe their reaction during the seizure, the majority reported a negative emotional response to the seizures. Twenty-four (48%) reported a feeling of fear, 13 (26%) reported a feeling of anxiety and 2 (4%) reported feeling hopeless. Four (8%) reported that they thought the child was going to die. Eighteen (36%) respondents

Table 1
Characteristics of parents and caregivers eligible for study.

	Interviewed, n = 50	Not interviewed, n = 21	p
Age of respondent, years, mean (SD)	33.8 (10.1)	32.3 (6.2)	0.53
Age of child, years, mean (SD)	4.6 (3.1)	5.1 (2.0)	0.50
Employment, N (%)	30 (60)	17 (81)	0.09
Previous seizure in child, N (%)	34 (68)	17 (81)	0.27
Seizure with fever in child, N (%)	22 (44)	7 (33.3)	0.40