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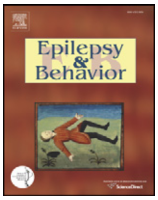

The effects of epilepsy on child education in Sierra Leone

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ABSTRACT

Epilepsy is associated with a significant burden of false beliefs and social stigma in the setting of Sub-Saharan Africa. To assess the impacts of epilepsy on child education in Sierra Leone (SL), we carried out a cross-sectional descriptive study examining its effects on school attendance, participation in physical activities, and social acceptance among classmates. We also assessed the knowledge, beliefs, and attitudes regarding epilepsy of both the children's caregivers and teachers.

The data were collected at various epilepsy clinics and schools in Freetown, SL. A total of 50 patients were interviewed and questionnaires administered to their caregivers and teachers, making a total of 150 respondents. Fifty-one percent of the children were absent from school for >5 days per month. Ninety percent did not participate in games and sports, with the commonest reason being fear of occurrence of seizures. Thirty-six percent claimed having experienced negative attitude from their classmates. Regarding the caregivers, 48% believed that epilepsy was a medical illness, while 34% considered it a demonic manifestation. Forty-eight percent were apprehensive about sending their children to school, with 83% of these caregivers stating fear of seizures and potential injuries. Only 8% of the caregivers did not prevent their children from taking part in any physical activity at school. Regarding the teachers, 16% believed that epilepsy was a demonic manifestation, and 10% thought that it was contagious. Fourteen percent did not think that children with epilepsy should go to school, and 80% would prevent children with epilepsy from participating in games and sports. When faced with a child having a seizure, 48% would hold the child down, 12% would place a hard object in the child's mouth, and 12% would avoid any physical contact. In total, 20% of the children ceased attending school permanently; daily occurrence of seizures ($p < 0.05$), negative attitude of classmates ($p < 0.001$), and having an illiterate caregiver ($p < 0.02$) all showed a significant association with permanent cessation of schooling.

The study demonstrates significant negative impacts of epilepsy on child education. Notably, the reasons for permanent exclusion from school appear to be as much related to attitudes as to the medical aspects of the disease itself. The data thus highlight the need for educational programs to address the widely prevalent misconceptions among both caregivers and teachers.

1. Introduction

Epilepsy is one of the commonest brain disorders, affecting at least 50 million people worldwide. The condition has serious physical, psychological, social, and economic consequences for affected persons and their families [1].

The annual incidence of epilepsy is highest in the youngest age groups, decreasing during childhood and among adults, and rising again in old age [2]. With a prevalence of around 7–8/1000 in children under the age of 11, epilepsy represents the most commonly encountered neurological condition in the pediatric population [3]. Worldwide, 10.5 million children under the age of 15 years are affected, with the same age group accounting for approximately 25% of the global annual incidence of 3.5 million people. Over 80% of the affected children live in developing countries [4].

The prevalence of epilepsy is substantially higher in Sierra Leone (SL) than in Western European countries, likely secondary to a range of factors including birth trauma, cerebral malaria, febrile convulsions, and meningitis. There have been no national studies in SL on epilepsy prevalence, but local reports suggest rates in excess of 1%, equating to over 60,000 people nationally [5].

Epilepsy can have far-reaching effects on patients, their families, and the community, and its impact on a person's quality of life can be greater than that of many other chronic conditions [6,7]. In numerous societies, people with epilepsy, particularly those with generalized tonic–clonic seizures, experience discrimination on a number of levels. The condition is often perceived as a mental illness, a manifestation of supernatural origin, or a contagious disease, and involuntary behavior associated

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Abbreviations: SL, Sierra Leone; AEDs, antiepileptic drugs.

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with some seizures, such as uncontrollable shaking or incontinence, tends to invoke fear and misunderstanding [1].

Social discrimination against people with epilepsy may in fact be far more damaging than the disease itself. One of the crucial domains influenced by epilepsy is education, with the affected children frequently receiving inadequate schooling [6]. Children with the condition often face marginalization and isolation, and previous surveys in schools revealed a high rate of social withdrawal among those affected [1]. The children may be rejected from their classes because of frequent seizures that make the teachers and fellow students uncomfortable [8], while others may be prevented from enrolling at school altogether once the educational authorities become aware of their history of epilepsy [9]. A study on the clinical and sociocultural aspects of epilepsy among Sierra Leoneans suggested that nearly half of the affected children discontinued schooling because of epilepsy [10].

Here, we present a study investigating the effects of epilepsy on child education in Freetown, SL. In particular, we examine how childhood epilepsy affects absence from school, the child's participation in physical activities at school, and the impact of their condition on social acceptance among their peers. We also report on the educational status of the children's caregivers, their beliefs about epilepsy, and their attitudes towards sending the affected children to school as well as assess the teachers' understanding of the condition, their beliefs and attitudes towards it, and their knowledge of appropriate first aid measures for epileptic seizures. In addition, we investigate potential risk factors that may predispose the affected children to permanent cessation of schooling.

2. Materials and methods

This cross-sectional descriptive study was carried out between February and April 2013. The data were collected at various epilepsy clinics (Connaught Hospital, Lumley Hospital, and Rokupa Clinic) and at a number of primary and secondary schools in Freetown, SL.

The study population consisted of boys and girls attending the aforementioned clinics who fulfilled the following criteria: i) known history of epilepsy, defined as being previously registered at the epilepsy clinic and treated with antiepileptic drugs (although no cross-check was made at the time of the study regarding the accuracy of the diagnosis); ii) attendance at a school in Freetown at the time of assessment in the clinic or within the previous 5 years, irrespective of age; iii) school authorities at the child's school aware of the child's history of epilepsy; and iv) ability of the child to independently answer the questionnaire. Children who were attending the clinic for the first time, children who were unable to express themselves adequately, children who attended school within the previous five years but had already completed secondary school, or those who refused to be interviewed were all excluded from the study.

The study was approved by the Community Health Department Research Committee of the College of Medicine and Allied Health Sciences in Freetown, Sierra Leone. The participants were informed about the purpose of the study, and verbal consent was obtained from the children and their caregivers (defined as a person responsible for the child and with whom the child was living permanently) before administering questionnaires. In cases where children were deemed to lack the capacity to provide informed consent, most commonly because of having a chronological or mental age that was too low, consent was obtained from their caregivers only. Participants were assured of absolute anonymity and confidentiality and advised that any information provided will be used for academic purposes only. Structured questionnaires (see Appendix) were administered to the selected children and their caregivers at the epilepsy clinics. The majority of the children were interviewed in the presence of their caregivers (with little interference); this allowed for cross-checking of the information provided by the children with regard to their seizure frequency. The children's schools were subsequently visited, and a questionnaire was used to collect data from their teachers.

3. Results and analysis

Fifty patients were included, together with their primary caregivers and teachers, making a total of 150 respondents. Ninety percent of the caregivers were the children's biological parents, with the remainder consisting of second-degree relatives. The response rate for the questionnaires administered to the selected participants, together with their caregivers and teachers, was 100%.

3.1. Information pertaining to the child

Of the 50 children interviewed, 52% were males and 48% females, with a mean age of 13.8 years (SD: ±4.7 years). Forty-six percent were in primary schools and 54% in secondary schools. As reported by the caregivers, the majority of the patients had a seizure either weekly ($n = 18$, 36%) or monthly ($n = 23$, 46%). Five (10%) children had seizures every day, while 4 (8%) had a seizure less than monthly.

Forty-one (82%) of the respondents missed at least one day per month of school because of epilepsy. Of those that did not miss school because of epilepsy, one had to eventually leave school permanently because of frequent seizures. Of those that regularly missed school, 27% were absent for less than 5 days per month, 29% for 5–9 days per month, 20% for 10–24 days per month, 2% stayed at home over 25 days per month, and 22% eventually ceased attending school permanently. The reasons given by the participants for their absence from school included being asked by their caregivers to stay at home (52%), high frequency of seizures (26%), feeling unwell after seizures (17%), and being asked by teachers to stay away from school (4%).

Of the 50 children, only 5 (10%) actively participated in games and sports at school. Twenty-four (53%) of those that did not participate did so because they feared that the physical activity would trigger a seizure and they would injure themselves. Twenty (44%) were advised by their caregivers or doctors not to participate. One (2%) of the children wanted to participate but was not allowed to do so by teachers or classmates.

Eighteen (36%) of the children claimed that their classmates had a negative attitude towards them (they ridiculed, provoked, or excluded them or considered them insane). On the other hand, 13 (26%) felt that their classmates were particularly careful around them, looked after them in school, and helped them when they had seizures. The remainder (38%) reported that their classmates were indifferent and did not treat them differently from other children in class.

3.2. Knowledge, attitude, and beliefs of caregivers

Of the 50 primary caregivers interviewed, 18 (36%) had no form of education at all, 7 (14%) had a primary education, 20 (40%) had a secondary education, 4 (8%) had a tertiary education, and 1 (2%) received Arabic education.

When asked about their beliefs about the causes of epilepsy, 24 (48%) caregivers believed it to be a medical illness, while 17 (34%) believed that it was a demonic manifestation. Three (6%) said that it was caused by witchcraft, 2 (4%) thought that it was caused by trauma, and 3 (6%) stated that they did not know. Only one (2%) respondent thought that epilepsy was contagious.

Regarding the caregivers' attitudes towards schooling, 24 (48%) of them were apprehensive about sending the affected children to school. Twenty (83%) of them said that they feared that their child would have a seizure in school and get injured. The remaining 4 (17%) said that it was because their child's seizures were frequent and usually severe. Of those that were not apprehensive about sending their child to school, 14 (54%) said that it was because of the importance of their child receiving education, 5 (19%) trusted the teachers to look out for and look after