Epilepsy & Behavior 33 (2014) 115–121

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Current beliefs and attitudes regarding epilepsy in Mali

Youssoufa Maiga [a,*], Mohamed Albakaye [a,b], Lanssana Laho Diallo [c], Broulaye Traoré [d], Yacouba Cissoko [e], Seybou Hassane [a], Sara Diakite [a], K. Clare McCaughey [b], Najib Kissani [b], Valeria Diaconu [f], Danielle Buch [g], Kassim Kayentoa [h], Lionel Carmant [f]

[a] Neurology Department, Gabriel Touré Teaching Hospital, PO Box 267, Bamako, Mali
[b] Neurology Department, Ibn Tofail Hospital, BP 7010, Sidi Abbad, Marrakesh 40000, Morocco
[c] Neurology Department, Hôpital Moderne de l'Amitié à Kipé, BP 3368, Guinea
[d] Pediatrics Department, Gabriel Touré Teaching Hospital, PO Box 267, Bamako, Mali
[e] Pediatrics Department, Hospital of Gao, PO Box 107, Gao, Mali
[f] Department of Pediatrics, Sainte-Justine Hospital (CHU Sainte-Justine), University of Montreal, 3175 Cote Sainte-Catherine, Suite 5421, Montreal, QC H3T 1C5, Canada
[g] Applied Clinical Research Unit, CHU Sainte-Justine Research Center, 3175 Cote Sainte-Catherine, Montreal, Quebec, Canada
[h] Malaria Research and Training Center (MRTC), Department of Epidemiology of Parasitic Disease, University of Bamako, Mali

ARTICLE INFO

Article history:
Received 19 November 2013
Revised 22 February 2014
Accepted 26 February 2014
Available online 19 March 2014

Keywords:
Stigma
Seizures
Education
Epilepsy
Africa
Mali
Belief
Attitude

ABSTRACT

Purpose: In Mali, epilepsy affects 15 individuals per thousand. Perceptions and attitudes have not seemingly evolved with advancing medical knowledge. The objective of this study was to assess parental beliefs and attitudes in families with and without affected children.
Methods: We enrolled 720 pediatric patients, half of whom had epilepsy, at Mali's largest hospital. We conducted semistructured interviews with the accompanying parent. Control families with unaffected patients and also had affected children were excluded.
Results: In total, 67% and 24% of families with and without epilepsy, respectively, lived in rural environments. Interviewees were mostly mothers in their 30s; 80% had not completed high school. About 22% of parents without an affected child had witnessed a seizure. During a seizure, 94% of parents with an affected child and 49% of parents without an affected child, respectively, would intervene; 7.5% and 21%, respectively, would wet the patient's face with cool water. Although parents with an affected child had more intimate knowledge of seizures, misconceptions prevailed, perhaps more so than in families without epilepsy: 79% and 66% of parents, respectively, considered epilepsy contagious; 43% vs. 69% thought that it inevitably led to psychosis; and 53% vs. 29% attributed epilepsy to supernatural causes. Finally, 63% of parents with an affected child reported consulting a traditional healer as first-line management for epilepsy.
Conclusions: Our study demonstrates widespread misconceptions in Mali regarding epilepsy. Our findings argue for more education initiatives focused on the entire population, including traditional healers, to provide knowledge, reduce stigma, and improve quality of life for individuals living with epilepsy.

1. Introduction

According to the World Health Organization, up to 94% of individuals with epilepsy in developing countries do not receive adequate treatment [1], resulting in a higher prevalence of active and lifetime epilepsy in those areas [2]. Lack of adequate treatment is, in part, due to incorrect beliefs and stigma associated with witchcraft and curses that have not evolved in the last half-century in Africa despite advances in scientific knowledge [3–8]. These perceptions and apprehensions vary by country and social context and may limit the implementation of individual or collective strategies to improve the quality of life of people living with epilepsy [9–12]. In Mali, high levels of illiteracy, lack of basic health education, and an absence of accurate information may combine to compromise the overall management of patients with epilepsy [4]. Clinical management is further impeded by obstacles related to low priorities on the part of governmental health authorities, poor health-care infrastructure, lack of or an irregular supply of seizure medication, high cost of available medications other than phenobarbital, inadequate social security, uneven geographical distribution of health-care centers, and shortage of qualified health-care professionals [13,14]. Mali, for example, has only two certified neurologists for a population of 13 million people, and both work in Bamako. Because of its chronic nature and high prevalence, epilepsy represents a major public health challenge in these countries with important socioeconomic consequences [15].

Many people affected by epilepsy in Mali live hidden in the shadows because of social stigmatization [4]. An initiative was, therefore,

* Corresponding author at: Neurology Department, Gabriel Touré Teaching Hospital, PO Box 1504, Bamako, Mali.
E-mail address: youssoufamaiga@hotmail.com (Y. Maiga).

http://dx.doi.org/10.1016/j.yebeh.2014.02.031
1525-5050/

launched by RARE (Réseau action-recherche sur l'épilepsie) in 1999 and extended in 2003 in Mali to bring primary physicians closer to rural communities and to provide inexpensive seizure medication. Compliance with treatment was subsequently evaluated, but the underlying attitudes in the community at large were not assessed [16]. In a preliminary study, we found that 49% of 423 families with children in an urban hospital and outpatient clinic thought that epilepsy was brought on by supernatural powers, and 59% considered the disorder contagious [17]. As only 15% of the parents in our sample had children with epilepsy, we wished to extend our research to a larger sample, half of which would represent families with affected children. Our main objective was, therefore, to further evaluate the knowledge and attitudes of parents in Mali while assessing whether these differed depending on whether the family had an affected child or not. Our ultimate goal was to document the need for a focused global education strategy, complementing efforts by RARE, to raise epilepsy awareness such that those in need of medical treatment might aspire to actively seeking and receiving it.

2. Methods

2.1. Participants

We conducted a questionnaire-based survey in 2007–2008, interviewing parents of children seen at the Gabriel Touré Hospital in Bamako, the capital of Mali. Gabriel Touré is the largest medical facility in Mali, a tertiary pediatric medical facility and teaching hospital. The study protocol was approved by the Institutional Review Board of the National Research in Public Heath Institute (INRSP, Institut National de Recherche en Santé Publique) in Bamako, Mali. All participants gave written informed consent.

Parents of children with epilepsy were systematically approached for enrollment during their child's regular consultation if the child was 0–15 years of age and the epilepsy was documented by the hospital's Department of Pediatrics or Neurology or both. Enrollment proceeded in the order of presentation. Parents of children without epilepsy were approached consecutively while their child was either hospitalized in the Department of Pediatrics or visiting a pediatric outpatient clinic for other illnesses; results of a preliminary study had determined that parental knowledge and beliefs were not associated with hospitalization or lack thereof [17]. Further, children in the groups with and without epilepsy were matched for age, sex, and parental level of education. Selection bias was, thus, avoided. For each enrolled child, we interviewed the accompanying parent. Parents in the group without epilepsy were excluded from the study if the interview determined that another of their children had epilepsy. Parents in the group without epilepsy were excluded from the study if, in the interview, we determined that they also had a child with epilepsy.

2.2. Questionnaire

Parents were interviewed during their child's hospital stay or outpatient visit by one of two investigators with clinical expertise in epilepsy (YM and MA). Both received the same training in questionnaires and were recruited for both groups. Interviews were semistructured and lasted 20–30 min. Data were collected on individual forms.

The questionnaire was adapted from a longer validated instrument for diagnosing epilepsy in tropical countries [18] that is used in other West African countries with populations similar to Mali's. Our shortened version consisted of 30 questions on sociodemographic characteristics as well as parental beliefs and attitudes regarding epilepsy based on our professional expertise with this population and our experience with its use in a previous study [17]. The questionnaire was translated into Bambara, the most widely spoken national language of Mali, for the benefit of those not fluent in French, the official language. An expert linguist from the National Directorate for Functional Literacy and Applied Linguistics (DNAFLA, Direction nationale de l'alphabétisation fonctionelle et de la linguistique appliquée) assisted in the translation. We tested the Bambara version in a hospital in Fana, another Mali city, for simplicity and completion time. This validation procedure helped us to better tailor questions and reduce their number.

2.3. Statistical analysis

Based on the pilot study, we determined the sample size using the Kish formula for survey sampling [17,19]. A sample size of 358 patients per group was determined to demonstrate statistically significant differences in beliefs, with significance set at $P < 0.05$.

We analyzed the data using SPSS software, version 12.6 (Chicago, IL). Participants were stratified by age and sex as well as by maternal level of education and socioeconomic status based on family revenue. Chi-square tests were used to compare categorical variables and Student's t-tests to compare quantitative variables. P values less than 0.05 were considered statistically significant.

3. Results

3.1. Participants

We identified 853 pediatric patients, with 381 being affected by epilepsy and 472 being unaffected (Fig. 1). For all but 10 children with epilepsy who were approached, the accompanying parent was recruited, mainly (87%) from the outpatient clinic. In the nonaffected group, 104 (22%) parents refused to participate, citing mainly lack of time and interest. Perhaps, those with hospitalized children had more disposable time, as reflected in the relatively high percentage of inpatients (46%). Altogether, we enrolled 371 and 368 participants in the groups with and without epilepsy, respectively and, after exclusions, analyzed 360 in each group.

In almost 80% of the cases, the accompanying parent was the mother (mean age 38.8 ± 8.9 vs. 34.1 ± 9.1 years, in the groups with and without epilepsy, respectively). Over 70% did not work outside the home (Table 1). Approximately 80% of the parents interviewed had not completed high school. Most families in the group with epilepsy (67%) lived in a rural environment compared with a mainly urban environment (76%) for the group without epilepsy. Nonetheless, 52% of families with epilepsy had an above-average income vs. 45% of those without despite the fact that the latter group was mostly urban.

The enrolled children in the group with epilepsy were slightly younger on average than those in the group without epilepsy (3.5 ± 2 years vs. 5 ± 3 for inpatients and 6 ± 4 years vs. 7 ± 3 for outpatients, respectively). As a group, children with epilepsy came from larger families compared with those without epilepsy (6.5 ± 3.3 vs. 4.7 ± 2.4, respectively), consistent with the greater number of urban families represented in the group without epilepsy.

3.2. Beliefs and attitudes

The main source of information regarding epilepsy was significantly different for the two groups. For parents of children with epilepsy, traditional healers (for 27% of the participants) and health-care professionals (for 24% of the participants) provided most of the knowledge, as well as the neighborhood, friends, and relatives (27%), while for parents without affected children, most of the information came from the neighborhood, friends, and relatives (for 51% of the participants), followed by the traditional healer (22%) (Table 2). School also played a larger part in the knowledge of those directly affected (19% vs. 9%) probably because the child was, thus, identified. The proportion of parents who heard about epilepsy primarily through the media was consequently very low (3%) in both groups.

While 38% of the parents with children with epilepsy understood that epilepsy was systemic in origin (compared with 68% of the others), fully 52% and 29% of the parents, respectively, believed that the disease