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Social Perception of Epilepsy among Caregivers of Epileptic Children in Bangui

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Abstract

Introduction: Epilepsy is one of the most common neurological conditions worldwide. It affects all age groups. Improved care is possible thanks to good knowledge of the disease. The objective of this study was to evaluate the perception of epilepsy among caregivers of epileptic children in Bangui with a view to contributing to the improvement of their care**. Patients and Methods:** This was a descriptive and exhaustive cross-sectional study among caregivers of children with epilepsy in four health facilities in Bangui from January 5 to July 5, 2023. **Results:** We surveyed a total of 80 caregivers. The majority of caregivers were aged 18 - 35. However, the real range was from 18 to 70 years old. Females predominated with a female-to-male sex ratio of 3.44. The majority of caregivers (90%) were at least educated. All those surveyed said they had heard about epilepsy previously (coming from neighborhood from friends and relatives). Among these caregivers, 36.36% believed that epilepsy was a contagious disease. The caregivers considered brain damage (48.75%) as the main possible cause of epilepsy. Most of the respondents (90%) are familiar with the clinical manifestation of grand mal type. The main triggering factors reported were Insomnia (26.25%) and emotional crises (25%). School difficulties (82.27%) were identified as the main complication in the life of an epileptic child. Half of the caregivers preferred modern medical treatment (antiepileptic drugs). 50% of the respondents considered epilepsy a medical condition, while 21.25% linked it to bad luck. Finally, 37.50% of caregivers took a child experiencing an epileptic seizure immediately to the hospital. **Conclusion:** At the end of this study, knowledge about epilepsy remains insufficient among parents of epileptic children in Bangui.

Keywords

Epilepsy, Perception, Caregivers, Children, Bangui

1. Introduction

Epilepsy is one of the most common neurological disorders in the world. Seizures result from excessive electrical discharges in a group of brain cells [1]. About 4 to 10% of children experience at least one seizure episode in the first 16 years of life. The mental impact of epilepsy is significant in children, with more than 30% experiencing varying degrees of developmental delay [2]. The prevalence is highest in children under 3 years old and decreases with age [3]. Parental knowledge and skills in epilepsy management are crucial, especially in handling epileptic seizures. Studies show that people with limited knowledge of epilepsy or without personal contact with someone with epilepsy tend to have poorer attitudes [4] [5]. Negative attitudes appear to be worsened by misconceptions about epilepsy, including its perception as a form of dementia [6], a contagious or hereditary condition [7], or a type of intellectual disability [8]. In sub-Saharan Africa, epilepsy has an average prevalence of 15.4‰ [9] [10]. In the Central African Republic, several studies have been conducted, either in schools or in the general population, and have shown prevalences varying from 2.8‰ to 49.5‰ respectively [11] [12]. Furthermore, studies among frontline healthcare workers [13] and traditional practitioners in Bangui have shown a lack of knowledge among the latter regarding epilepsy [14]. Parental knowledge and understanding of childhood epilepsy must be improved. Many parents hold misconceptions and exhibit poor attitudes and practices [15]. With this in mind, we conducted this study to assess caregiver's understanding of epilepsy in children receiving care in Bangui.

2. Patients and Methods

We conducted a descriptive and comprehensive cross-sectional study among caregivers of children with epilepsy in four health facilities in Bangui (Pediatric University Complex of Bangui, DREAM Sainte EGIDIO clinic, Mother and Child Center and Mama Carla Clinic) from January 5 to July 5, 2023. Caregivers of both genders aged 18 years or older were included in the study. They were present at the bedside of sick children and actively caring for them at the time of the study. Data were collected using a questionnaire covering sociodemographic aspects, as well as respondents' knowledge, attitudes and practices regarding epilepsy. The data were entered and analyzed using EPI-INFO Version 7.2.2.6 software.

3. Results

We surveyed a total of 80 caregivers. The age group of 18 - 35 years was the majority. The predominance was female, with a sex ratio F/M of 3.44 (**Table 1**). The majority of caregivers (90%) were educated. More than half (51.25%) of caregivers were the children's parents; most had reached secondary school and were in business.

All respondents said they had heard of epilepsy in society. Among these caregivers, 36.36% thought that epilepsy was a contagious disease. Brain damage (48.75%) was considered the main cause of epilepsy. Most respondents (90%) reported the clinical manifestation of grand mal type. Insomnia (26.25%) and emotional crisis (25%) were the main triggering factors cited by respondents. Half of the caregivers preferred modern treatment. Half of the respondents considered epilepsy to be a medical condition, and 21.25% associated it with bad luck (**Table 2**). The ban concerned the consumption of monkey meat.

Table 1. Distribution of respondents according to age and sex.

Age Groups	**Sex**		**Total**
	F	**M**	
18 - 35	33	10	43
36 - 44	15	5	20
45 - 69	12	2	14
>70	2	1	3
TOTAL	62	18	80

Table 2. Distribution of respondents according to their belief on the nature of epilepsy.

Belief of Respondents	**Number**	**Percentage**
Medical pathology	40	50%
Bad spell	17	21.2
Paralytic disease	5	6.3
Symptom of disease	3	3.7
Possession by an evil spirit	1	1.3
Don't know	14	17.5
Total	80	100%

Almost half of the caregivers (37.50%) took the child with an epileptic seizure immediately to the hospital (**Table 3**).

Table 3. Practical conduct of respondents during an epileptic seizure.

Attitudes of Respondents	**Number**	**Percentage**
Drive to the hospital	30	37.5
Pour water on the face	27	33.7
Driving to a fetish priest	6	7.5
Wake the child up by shaking him	2	2.5
Don't know	15	18.8
Total	80	100%

4. Discussion

This is the first study conducted in the Central African Republic among caregivers of epileptic children. Our work has just assessed the knowledge, perception, attitudes and practices of caregivers on childhood epilepsy in Bangui.

Age and sex: During our study, we found that most caregivers were aged 18 - 35. Our finding differs from the study that was done in Türkiye [16], which showed a higher age group of 41 to 60 years. This finding reflects the structure of the young population in our country. Our study also showed that the majority of caregivers were female. This trend is culturally reflected by the fact that mothers are the people who often accompany children to consultations in the Central African Republic.

Level of education: In our study, the majority of caregivers 90% were at least educated, and the remaining 10% were illiterate. Among these respondents, 15% had a higher education level. This observation differs from a Turkish series [16], which reported that 34.80% of the population was illiterate and only 16.50% had reached a higher education level. This high rate of schooling in our study would contribute to dispelling rumors about epileptic disease.

Source of information: All respondents said they had heard about epilepsy in society (neighborhood from friends and relatives) before their child was diagnosed. This same assertion was reported by traditional practitioners in a study in Bangui [14]. This observation differs from a Malian series [17] in which 18.50% heard about the disease during their training and 26.10% with health personnel. Communication about epileptic disease should be strengthened through weekly radio broadcasts. Contagiousness of the disease: Nearly half of caregivers (36.36%) considered epilepsy to be a contagious disease. We noted that this notion of contagiousness was significantly expressed in the Central African Republic in several studies [11] [14] conducted in the general population in the east of the country and in schools in Bangui. This result is significantly higher than that reported in Nigeria (6.91%) in a study among medical and science students [18]. This assertion in our series shows the lack of knowledge about epileptic disease on the one hand and the low level of education among caregivers on the other hand. We can also highlight the fact that our country has fewer neurologists and not yet a neuropediatrician, hence the low level of awareness about epilepsy.

Causes of epilepsy: Brain damage (48.75%) was considered the main cause of epilepsy by caregivers. Some of them (6.25%) thought there was no cause. Our findings corroborate that of a study at the Gabriel Touré University Hospital [19], which found respectively among respondents (50.70%) and (5.20%). This result shows that the respondents know the organs affected by epileptic disease.

Functional signs: The clinical manifestation recognized by caregivers was the grand mal tonic-clonic type (90%). This finding is similar to that reported in a study [14] in Bangui among traditional practitioners and those reported in other studies in Africa [20]-[22] and thus reflects the ignorance of other forms of epilepsy that could go unnoticed and be a source of poor referral to inappropriate care structures.

Factors triggering epileptic seizures: Insomnia and emotional crisis were the main triggers of epileptic seizures spontaneously cited by respondents, respectively 26.25% and 25.00%. This finding was also reported in a study in Dakar [22] in which insomnia and stress are considered as triggers of seizures. This assertion reflects an average level of knowledge regarding the factors triggering epileptic seizures.

Secondary neurological complications: School difficulties (89.78%) and death (6.33%) represented the main complications in the life of an epileptic child identified by the respondents. The same observation was reported in a Malian series [21] in which intellectual disabilities represented (40.00%) and deaths (18.90%). This observation could be explained by the lack of information on the disease.

Stigmatizing aspect of epilepsy: More than half of the caregivers felt that the disease led to stigmatization of the child. The mode of contamination by saliva wrongly expressed by some respondents is often the cause of stigmatization. The same observation was made in several studies in Africa [11] [15] [22]. This is the perception of the disease by African society, which would contribute to the denial of patients, and would not allow epilepsy to come out of the shadows as desired by the WHO.

Treatment and cure of epilepsy: More than half of caregivers (52%) would prefer modern treatment for their children. This preference for modern treatment was reported in a Saudi series [23] (61.20%). In our study, the majority of caregivers (75%) had hope for the cure of the child with epileptic disease, unlike 20% of them. This observation shows the attachment of parents to modern treatment, hence the need for good collaboration between neurologists, other specialists and the family, to prevent the morbid process and contribute to the referral of epileptics to the appropriate care structures.

Beliefs: Half of the respondents considered epilepsy as a medical condition and (21.25%) of them believed that it was linked to bad luck. This cultural apprehension was also found in a study among traditional practitioners in Bangui [14]. These erroneous beliefs about epilepsy are already known in other African and Third World countries [16] [24] [25]. This finding reflects the poor perception and the importance of erroneous beliefs about epilepsy. Attitudes and practices: Nearly half of the caregivers (37.50%) thought that the child with an epileptic seizure should be taken immediately to the hospital, (33.75%) of them believed that water should be poured on the face straight away and (18.75%) preferred not to do so. Our results are close to a Saudi series in which (33.10%) thought that the epileptic should be placed on one side until consciousness was regained, (22.00%) immediately poured water on the face and (34.90%) preferred to abstain [23]. The attitude of keeping the child on the side during the seizure is a protective attitude that should be encouraged, because the epileptic in crisis is a vulnerable person in danger who must be rescued. The majority of our respondents have already assisted an epileptic child during his seizures. Our series also shows that (55%) of caregivers systematically gave the child a painkiller after the seizure, (18.75%) believed that he only needed to be monitored and (2.50%) opted to take him directly to the hospital. This could be explained by the fact that most of the respondents were unaware of the emergency procedures for an epileptic seizure. Information, education and communication are therefore very important.

5. Conclusion

At the end of this study, we assessed the knowledge, beliefs, attitudes and practices of caregivers of epileptic children regarding epileptic seizures. The results of this study are that most of the respondents were aged 18 to 35, the majority of whom are housewives with at least some education. They have an insufficient level of knowledge about childhood epilepsy. The attitudes and practices of the respondents were not really adapted in the event of an epileptic seizure.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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