



Socio-cultural representation of epilepsy at the teaching hospital of point G, Mali

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ABSTRACT

Background: Epilepsy is a significant public health concern with psychosocial impacts, including fear, stigma, and misconceptions. These factors contribute to human rights violations and discrimination. The objective of this study was to describe the sociocultural representation of epilepsy in Mali.

Materials and methods: This cross-sectional descriptive study was carried out from April 2015 to November 2016 at the University Hospital of Point G. Patients with epilepsy were identified prospectively, and a questionnaire was administered to each patient and their parents.

Results: A total of 104 patients were enrolled with an average age of 35 years, ranging from 15 to 89 years. Males were slightly predominant, accounting for 53.85%, resulting in a sex ratio (M/F) of 1.17. In terms of occupation, workers comprised 68.27% of participants. Patients residing in urban areas represented 61.54%, and the most level of education was secondary (40.38%). The majority of patients (57.69%) and their relatives (69.23%) thought that epilepsy was caused by mystical causes. Stigma was reported by 66.35% of our patients.

Conclusion: The sociocultural perception of epilepsy hinders evidence-based diagnosis and management in Africa. This study suggests a need to focus on raising awareness to change these misconceptions.

1. Introduction

Epilepsy is a significant public health concern surrounded by fear, stigma, and misconceptions which often lead to human rights violations and discrimination. While the primary challenges faced by individuals with epilepsy in their daily lives are not only related to the disease itself, but rather stem from some prevailing misconceptions held by the general public [1]. The socio-cultural representation of epilepsy perpetuates prejudices that strongly impact epileptic patients (EP) and their parents, resulting in delaying access to care and disrupting social relationships.

In Africa, traditional beliefs and empirical notions about epilepsy have remained resistant to change, despite the considerable advancements in evidence-based medicine [2]. Furthermore, psychosocial repercussions affect persons with disabilities, leading to stigmatization and marginalization within society. While stigma exists to varying degrees globally, its impact is more pronounced in developing countries like Mali. The burden of epilepsy such countries affect not only EP but

also their families. People living with epilepsy (PLE) are affected by physical risks during seizures, including the potential for injury and fatality. For instance, a child with epilepsy in a low-income family may not be able to participate in everyday family activities like fetching water due to a fear of drowning or cooking for fear of falling into a fire [3]. Stigmatization further isolates them, resulting in limited friendships play opportunities during childhood [4]. In most African countries, despite increasing medical understanding of epilepsy, harmful beliefs and misconceptions persist, exacerbating the prognosis, experience and management of the condition [5].

Overall, limited data exists to comprehensively assess the impact of epilepsy on quality of life. Previous studies indicates a notably negative impact on PLE and their families [3]. Studies from China have highlighted elevated rates of stigma experienced by PLE and their families [6]. In Asia, the misconception that epilepsy is solely hereditary is a common belief, leading to such a difficulty in marriage for PLE and negative implications for the entire family [7].

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In this study, our aim was to elucidate the sociocultural representation of epilepsy, with the intention to improve its prognosis, the quality of life for those with epilepsy and their care at the Point G teaching hospital.

2. Patients and methods

This study was conducted in full compliance of the Declaration of Helsinki. Informed consent was obtained from patients and/or guardians or parents in the case of minors. A cross-sectional study was carried out over a period of 18 months, spanning from April 2015 to November 2016 at the Department of Neurology of the Point G teaching hospital. The study encompassed all epilepsy cases diagnosed in four departments namely Neurology, Infectious Diseases, Cardiology, Psychiatry. The diagnosis of epilepsy was established according to the guideline of the International League against Epilepsy (ILAE) version 2014 [8]. This study included all patients aged 15 years or older, clinically diagnosed with epilepsy and/or confirmed through an electroencephalogram (EEG), with complete clinical records, and having been on antiepileptic medication for at least 3 months. Patients under 15 years of age and those who did not receive epilepsy treatment or undergo an EEG were excluded. Sociodemographic characteristics, as well as the disease perception by the patients and parents were analyzed. An individual survey form was employed to collect information provided by patients and relatives during this study. Both outpatients and inpatients, and those who came to undergo EEG in the neurology department, responded to the survey questions after giving informed consent and meeting the inclusion criteria. Data were entered into Excel. Data quality control was performed to ensure the accuracy of the data between the card survey and the Excel database. The Excel database was subsequently imported into SPSS Version 23 for descriptive analyses.

3. Results

A total of 104 patients were enrolled in this study with men were accounting for the majority 53.85%, compared to women. The age group most prominently represented was those under 40 years, constituting 67.31%. A majority of participants hailed from urban areas, totaling 61.5%. The prevalent level of education among patients was secondary, encompassing 40.38%. Regarding etiology, a significant proportion of patients (57.69%) attributed epilepsy to mystical phenomena, while 69.23% of their relatives held the same belief. Among the cases, 33.65% were not subjected to stigma, whereas 37.5% of parents dramatized the disease. The primary types of stigma and their proportions are outlined in Table I.

4. Discussion

In recent years, significant progress has been made in the management and integration of PLE in developed countries. However, the issue remains plagued by stigma and misconceptions in developing countries. We conducted a prospective study within the neurology department of the University Hospital of Point G. The average age was 35 years with extreme ranging from 15 to 89 years. The most represented age group

was under 40 years or 67.31% ($N = 104$). Similar findings were reported in Mali (87%) and Benin (82.9%) by Assogba H.J et al. and Houeto S et al., respectively [9,10]. This trend could be attributed to the multitude of risk factors within this age group.

Males were predominantly represented, similar to other studies in developing countries [11,12]. Patients and their parents who thought epilepsy was related to mystical phenomena accounted for 57.69% and 69.23%, respectively. A study conducted in Mali by Albakaye M.Y et al. found that 38% of participants attributed the disease to supernatural causes [13]. Traditional African beliefs are that epilepsy is a spiritual disease caused by evil spirits, witchcraft, and even excessive palm oil consumption [14]. Millogo's research reported that epilepsy was attributed to hereditary factors in 40%, food consumption in 20%, and spirits in 16% [15]. A study by Nubukpo P et al. in Togo found 53.5% ($N = 129$) and in Benin, 44.3% ($N = 99$) believed that epilepsy was of supernatural factors [16]. Nearly half of the epileptic patients in sub-Saharan Africa believed in the supernatural origin of their epilepsy. The etiologies of epilepsy are multiple and depend on beliefs in each country and ethnic group, explaining why patients prefer to see traditional practitioner for their treatment [3]. In our study the majority of participants, 66.35% of patients reported some form of stigmatization and the most commonly reported form of stigma was "devaluation" reported in 29.81%, followed by rejection in 19.23%. This result is similar to that of Rafael F et al. in Benin who found that out of 80 people with epilepsy, about 68.7% reported feeling stigmatized [17]. Other similar results were reported where nearly half, and sometimes as much as 70%, of people with disabilities reported feeling stigmatized in the United States, United Kingdom and France [18–21]. This result demonstrates the burden of stigma faced by many epileptic patients. Generally, epileptic patients are tolerated but seem not to contribute to their social activities or development [22]. This disease may lead to family, social and occupational disqualifications [23,24]. In addition, patients described stigma from their parents, reported in 86.5% in this study. The most commonly reported form of parental stigma was dramatizing the disease in 37.5%, followed by lack of attention in 19.23%, and fear in 17.31%. This fear can be explained by the fact that epilepsy is presented as a highly contagious disease, spreading via saliva, urine, blood, and even feces [25,26]. This is the main reason why people with epilepsy may not get assistance from other people or marry them. Moreover, the period of seizures is believed to be the stage when such a person is most contagious. In the Dogon cities in Mali, attitudes of fear during the crises lead the entourage to leave the patient alone [27]. Lack of knowledge, misbehaviors, and inappropriate beliefs regarding epilepsy contribute to stigma and decrease their quality of life [28]. This can also influence the ability of the patients to manage their disease or receive support from their families. Hence, there is urgent need for widespread awareness and education campaigns involving local authorities.

This study does have limitations. It was carried out solely at a single center of the country which limits its ability to address epidemiological gaps across the entire country. Similar studies should be conducted in other regions of the country to better assess the overall psychosocial burden experienced by people living with epilepsy, ultimately leading to better care.

5. Conclusion

The socio-cultural perception of epilepsy presents challenges for its effective management in Africa. This study suggests emphasizing the need to develop culturally appropriate awareness campaigns involving local authorities to disseminate accurate information about epilepsy, leading to a shift in attitudes within developing countries. Such efforts can help ensure better access to care and an improved quality of life for individuals living with epilepsy.

Table I
Distribution of primary type of stigma for parents.

Types of Stigma	Frequency	Percentage
Dramatize	39	37.5
Lack of attention	20	19.2
Fear	18	17.3
Unstigmatized	14	13.5
Sleep alone	5	4.8
Eats alone	4	3.8
Don't get married	4	3.8
Total	104	100

Author contributions

Coulibaly Th: Design of the study, and acquisition, analysis and interpretation of data and editing the manuscript.

Dicko OA: Data acquisition and drafting the manuscript.

Sangaré M: Data analysis and editing the manuscript.

Sissoko AS: Data acquisition and analysis.

Cissé L: Data acquisition and editing the manuscript.

Landouré G: Data acquisition, interpretation and supervision.

Djimé S.O: Data acquisition and interpretation.

Yalcouyé A: Editing the manuscript, review and critique.

Coulibaly T: Data acquisition and supervision.

Karambé M: Data acquisition and interpretation, and supervision.

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CRediT authorship contribution statement

Th Coulibaly: Conceptualization, Resources, Supervision, Investigation, Data curation, Formal analysis. **O.A. Dicko:** Validation, Formal analysis, Data curation. **M. Sangaré:** Supervision, Resources, Data curation. **A.S. Sissoko:** Investigation, Data curation. **L. Cissé:** Visualization, Validation, Supervision. **G. Landouré:** Validation, Supervision, Data curation, Conceptualization. **S.O. Djimé:** Investigation, Formal analysis, Data curation. **A. Yalcouyé:** Data curation, Writing - review & editing. **T Coulibaly:** Investigation, Conceptualization. **M. Karambé:** Supervision, Investigation. **Y.M. Maiga:** Formal analysis, Data curation. **C.O. Guinto:** Supervision, Resources, Methodology, Investigation, Formal analysis, Conceptualization.

Declaration of Competing Interest

We declare there are no competing interests.

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