Seizure: European Journal of Epilepsy 67 (2019) 23–26

Contents lists available at ScienceDirect

Seizure: European Journal of Epilepsy

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

# Sociocultural representations of epilepsy in the Central African Republic: A door-to-door survey

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ARTICLE INFO

*Keywords:*
Epilepsy
Central African Republic
Door-to-door survey
Sociocultural
Misconception
Misrepresentations
Prevalence

ABSTRACT

*Purpose:* To describe sociocultural representations of epilepsy in a sub-Saharan Africa rural community using a population-based approach.
*Method:* A cross-sectional door-to-door survey was underway on a rural community of the Central African Republic in 2015. A two-stage stratified sampling was performed. Trained care personnel performed individual face-to-face interviews. A standardized questionnaire was used to assess epilepsy. We collected socio-demographic data and cultural representations toward epilepsy in general population.
*Results:* Overall, 1023 participants were interviewed. Epilepsy prevalence was 11.7 (95%CI 6.7–20.4) per 1000 people. In the rural community, epilepsy was identified as a supernatural disease related to bad luck (40.4%), witchcraft (31.3%) or a curse (28.3%). Epilepsy was confused with a mental disorder in 75.9% of subjects. Three quarters of participants (75.3%) considered epilepsy as a contagious disease. Saliva was mainly mentioned as a means of transmission in 63.8%. More than half of participants preferred or recommended traditional treatments. Only 24.8% believed in the efficacy of medical treatment for epilepsy.
*Conclusions:* Epilepsy misconceptions are highly prevalent in rural sub-Saharan Africa. Understanding misrepresentations is an essential phase to develop culturally appropriate interventional programs in order to improve medical treatment adherence, quality of life, and to decrease stigma. Campaigns to raise awareness are needed in urban and rural population to reduce misconception and combat stigmatization.

## 1. Introduction

Epilepsy is the most common chronic neurological disorder with a global estimate of about 70 million cases of lifetime epilepsy [1]. More than 80% of people with epilepsy (PWE) live in developing countries [2]. The median lifetime epilepsy prevalence has been reported at 15.4 per 1000 for rural and 10.3 for urban studies in developing countries [1]. Epilepsy prevalence in sub-Saharan Africa varies widely from country to country due to different risk factors [3]. A meta-analysis found that the global prevalence of epilepsy was 9.39 per 1000 in sub-Saharan Africa [3]. Only one epidemiological study has been performed in the Central African Republic that found a prevalence of 2.8 per 1000 people using a school-based approach [4].

Epilepsy is a major public health problem surrounded by fear, stigma, and misconceptions that lead to human rights violations and discrimination [5]. Misconceptions and misrepresentations of epilepsy, such as confusion between epilepsy and mental illness or suspicion of supernatural origin, promote negative attitude towards PWE. Epilepsy misunderstanding based on myths and superstitions, which appear to be influenced by psychosocial and cultural factors, have a negative influence on the quality of life and social integration of PWE factors [6,7]. Sociocultural attitudes that promote stigma could affect the management of epilepsy [8]. PWE with higher levels of perceived stigma reported lower medication adherence [9] or they were more likely to miss taking their antiepileptic drugs [10]. For these reasons, the International League Against Epilepsy, the International Bureau for Epilepsy and the World Health Organization launched the global awareness campaign “Out of the Shadows” more than two decades ago [11]. The African declaration on epilepsy also called for public health measures to raise professional and public awareness to fight against ill-informed

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https://doi.org/10.1016/j.seizure.2019.02.018
Received 16 December 2018; Received in revised form 10 February 2019; Accepted 26 February 2019

attitudes [12]. Considering all these efforts to increase epilepsy awareness, it is important to assess if there have been any changes in some rural communities in sub-Saharan Africa. In this context, we aimed to describe sociocultural representations toward epilepsy in a rural community using a population-based approach.

## 2. Methods

### 2.1. Study area and population

A cross-sectional door-to-door survey was underway on the community of Berbérati, located in the west of the Central African Republic (CAR), from January to March 2015. The CAR is a low-income country going through a long path of recovery after a military-political crisis. Berbérati is a mostly rural community located at 600 km from the capital city, Bangui. The community is divided on 7 departments and 61 neighbourhoods covering an area of 67 $km^2$. A total population of 76,918 inhabitants was estimated in 2003 census. Several ethnic groups, such as Bianda, Bogongo, Mbimon, Ngombé, Bogodo, Bogongo, Bongbélengue, Souma, or Gbaya de Bossangoa, live in the area. The official national language named Sango is the most commonly spoken. Farming, fishing and mining are the main economic activities in the community.

### 2.2. Sampling and inclusion criteria

The sample size was calculated considering the prevalence of epilepsy estimated in Bangui [4] and a precision of 0.025. A two-stage stratified sampling was performed. The primary sampling units were the districts that were selected using a simple random sample. A homogenous distribution of the sample size was used to obtain the number of people per district. Subsequently, the neighbourhoods were randomly selected using a proportional to the size approach. Participants included had to meet the following criteria: people who were able to express themselves verbally and were aged greater than or equal to 10 years.

### 2.3. Data collection and statistical analysis

The data were collected using an *ad hoc* survey form composed of 19 items and adapted from the standardized questionnaire on epilepsy developed by the Limoges Institute of Epidemiology and Tropical Neurology (NET) [13,14]. All the participants were individually interviewed. A medical student with training on epilepsy conducted the interviews. Epilepsy was defined as a condition characterized by recurrent seizures, at least two unprovoked, occurring in a period of more than 24 h [15]. Sociodemographic data and cultural representations toward epilepsy were collected in general population.

Data analyses were performed using Epi Info software version 3.5.4. Quantitative variables were expressed as means and qualitative variables as frequencies and percentages. All missing data were reported. The significance threshold was set at 0.05.

### 2.4. Ethical considerations

Participants were informed of the purpose of the survey. The informed consent was individually given by signing a consent form before the interview. The study followed all the dictates of the Declaration of Helsinki.

## 3. Results

### 3.1. Epilepsy prevalence

Overall, 1023 participants were interviewed in the door-to-door survey. Twelve people with epilepsy were found which leads to a prevalence of 11.73 (95%CI 6.67–20.39) per 1000 people. More than half PWE were under 29 years and unemployed. 58.3% of PWE lived with partners (married/cohabiting). Sociodemographic characteristics of PWE are shown in Table 1.

**Table 1**
Sociodemographic characteristics of participants and people with epilepsy in a rural community of the Central African Republic.

| Sociodemographic | Participants (n = 1023) | | People with Epilepsy (n = 12) | |
|---|---|---|---|---|
| | n | (%) | n | (%) |
| **Sex** | | | | |
| Male | 461 | (45.1) | 6 | (50.0) |
| Female | 562 | (54.9) | 6 | (50.0) |
| **Age groups** | | | | |
| 10-19 years | 325 | (31.8) | 2 | (16.7) |
| 20-29 years | 290 | (28.3) | 6 | (50.0) |
| 30-39 years | 190 | (18.6) | 1 | (8.3) |
| 40-49 years | 119 | (11.6) | 0 | (0.0) |
| ≥ 50 years | 99 | (9.7) | 3 | (25.0) |
| **Employment status** | | | | |
| Farmer | 391 | (38.2) | 4 | (33.3) |
| Student | 212 | (20.7) | 0 | (0.0) |
| Trader/Craftsman | 207 | (20.2) | 2 | (16.7) |
| Civil servant | 182 | (17.8) | 0 | (0.0) |
| Unemployed | 31 | (3.1) | 6 | (50.0) |
| **Religion** | | | | |
| Christian | 1004 | (98.1) | 8 | (66.7) |
| Muslim | 19 | (1.9) | 4 | (33.3) |
| **Schooling** | | | | |
| Yes | 858 | (83.9) | 7 | (58.3) |
| No | 165 | (16.1) | 5 | (41.6) |

### 3.2. Sociodemographic characteristics of the participants

Most participants were female (54.9%) with a male/female sex ratio of 0.82. The mean age was 45 years. A high proportion of participants were farmers. More than four fifths (83.9%) had received formal schooling (47.7% primary level, 34.4% secondary level, and 1.8% tertiary level) and 16.1% were illiterate. Sociodemographic characteristics of the participants are shown in Table 1.

### 3.3. Sociocultural representation of epilepsy

In the rural community, 74.8% of the participants were aware of epilepsy. Generalized tonic-clonic seizures were the most recognized entity (83.3%). Epilepsy was identified as a supernatural disease related to bad luck (40.4%), witchcraft (31.3%) or a curse (28.3%). Other etiologies were also mentioned as brain damage (52.9%), hereditary (43.2%) and alcohol abuse (29.3%). Epilepsy was confused with a mental disorder in 75.9%. Three quarters (75.3%) considered epilepsy as a contagious disease, particularly in female participants (56.3%) and people under 29 years (74.9%). Saliva was mainly mentioned as a means of transmission (63.8%). 71.9% admitted having attitudes that promote stigma, for example, they did not want to use objects that had been in contact with people with epilepsy.

More than half (52%) of participants considered that epilepsy was curable through traditional treatment, and preferred or recommended traditional treatments. Only 24.8% believed in the efficacy of medical treatment for epilepsy. Nevertheless, a high proportion of participants recommended seeking care with health personnel to manage epilepsy. The health-seeking itinerary recommended by the general population are shown in Table 2.

**Table 2**
Health-seeking itinerary recommended by the general population.

| | n | (%) |
|---|---|---|
| **Personnel recommended** | | |
| Health care personnel, yes | 491 | (48.0%) |
| Traditional healer, yes | 320 | (31.3%) |
| Religious personnel, yes | 137 | (13.4%) |
| I do not know | 75 | (7.3%) |
| **Institution recommended** | | |
| Hospital/clinic, yes | 484 | (47.3%) |
| Traditional healer, yes | 319 | (31.2%) |
| Religious institution, yes | 140 | (13.7%) |
| I do not know | 80 | (7.8%) |

## 4. Discussion

This study showed that epilepsy misconceptions are highly prevalent in rural sub-Saharan Africa. General population in rural communities still consider epilepsy as a mental illness or as a contagious disorder with a supernatural origin, which promote negative attitudes and make the social integration of PWE difficult. Traditional medicine has a major role due to the high confidence in traditional healers among rural population.

Epilepsy prevalence in rural areas of the CAR was consistent with previous reports across sub-Saharan Africa [16–19]. In our study, we have considered population older than 10 years. Epilepsy affects people of all ages, so we could assume that prevalence could be higher. We performed a door-to-door survey using a standardized questionnaire to estimate epilepsy prevalence. A stratified sampling was used to assure homogenous distribution of the sample in the general population. Despite our efforts, we cannot exclude that some people hide their condition due to related epilepsy-related-stigma.

Sociocultural misrepresentations have an important role on several psychosocial aspects such as stigma, discrimination, or social integration of PWE. Studies showed that PWE suffer from familial and social marginalization due to epilepsy [20]. In rural areas, PWE are excluded to participate in activities such as collecting water for fear of drowning, or cooking for fear of falling in the fire [21]. There is anecdotal evidence in Africa of 1960 that PWE were forced to be isolate into a shelter, or to leave home to hide in the countryside [22]. Even nowadays, social isolation has been reported as high as 67% in rural communities of Cameroon [23]. Social rejection is frequently experienced due to held misconceptions of epilepsy etiologies [24]. African population still believe that epilepsy is a contagious disease, as we showed in our study. Similar results have been reported in Benin [25], Burkina Faso [26] and Burundi [27]. We also found comparable representations of the relation between epilepsy and alcohol [25] or genetic predisposition [28]. A study in urban areas of the CAR found that 28.8% believed that epilepsy was due to bad luck, and 45.0% to an evil spirit [4,29]. Another study in CAR described that 54% of PWE believed that the disease was contagious, 55.6% that it was incurable, and 20.9% that it was due occult or supernatural causes [30]. A study in Benin found that witchcraft was mentioned as the most frequent cause of epilepsy in rural communities [25]. Almost half of PWE in sub-Saharan Africa believed on the supernatural origin of their epilepsy, as it was shown in a study in Togo (53.5%) and Benin (44.3%) [8]. Suspected demoniac origin of epilepsy could affect health-care seeking behavior. PWE could prefer to seek traditional medicine to confront a disease due to a supernatural origin [21].

Cultural beliefs stigmatize people with negative stereotypes [31] and epilepsy is felt to be a stigmatizing condition worldwide [32]. A European study reported more than half of PWE experienced stigmatization [33]. In Latin America, 65.8% reported feeling stigmatized and 39.1% reported a high-stigmatized level [34]. In Africa, 68.7% of PWE experienced stigmatization related to their condition [35]. Further studies are needed to understand the specific role of sociocultural misconceptions in epilepsy stigma, especially in areas where these erroneous representations are highly prevalent.

Social negative attitudes towards epilepsy and mainly stigma could be associated to psychosocial difficulties and psychiatric comorbidities such as poor self-esteem, social isolation, anxiety, improper social skills, depression, and emotional distress [36]. Several epidemiological studies have reported a higher prevalence of depression and anxiety in PWE [37,38]. A meta-analysis found that the overall pooled prevalence were 23.1% for active depression and 13.0% for lifetime depression [39]. A substantial treatment gap is evident in developing countries. In those countries, about 60% of patients with epilepsy receive no antiepileptic treatment [3] related to several causes. Sociocultural misrepresentation of epilepsy is one of many factors involved in the treatment gap. PWE tend to hide their epilepsy due to cultural beliefs [40], which could have a negative effect on the disease management. A study in rural Kenya reported that reduced adherence to treatment was associated with negative attitudes about epilepsy (adjusted odds ratio 1.10, CI 1·03–1·18) [41]. Therefore, sociocultural attitudes should be taken into account in the management of the disease [8].

Misconception is a complex social construction with all the associated consequences that could explain, at least partially, unequal opportunities in employment and education for PWE [42]. In an effort to determine the factors associated to epilepsy misconception in sub-Saharan Africa, a systematic review found that perceptions of how epilepsy affects people with epilepsy were significantly associated with rural residence, the male sex, and lower education [43].

In our study, most people with epilepsy have lower educational level, no employment and two-fifths were not married. These could be related to the high prevalence of misconceptions in the rural community. Epilepsy was considered a mental disorder and a contagious condition. These misconceptions make more difficult to achieve social integration and they promote the lack of opportunities to work or to study for PWE.

We found that rural communities had more confidence in traditional medicine. PWE could prefer to seek traditional healers rather than medical care. According to the World Health Organization, 60% of the world's population use traditional medicines [44]. An epilepsy study showed that traditional medicine seems to be PWE's first choice for treating their disease [45]. Consequently, it would be appropriate to establish collaboration between traditional healers and medical care professionals. A collaboration could improve the identification of PWE that are treated only by traditional healers. A pluri-disciplinary management could be consider using conventional medicine to control seizures and traditional medicine to support socio-psychological aspects respecting the heritage of each culture. Furthermore, it would be interesting to assess the pharmacological effects and safety of medicinal plants used mostly by traditional healers on predictive models of seizures [46].

There are several limitations to consider in the study. First, we estimated prevalence considering population older than 10 years, thus prevalence of epilepsy might be underestimated. Second, women and under 29 years population were mostly represented in the survey, which correspond to the sociodemographic characteristics of the CAR population. Lastly, we were not able to determine the association between sociocultural representation and social consequences as stigma or social isolation of PWE. On the other hand, the study relies on certain strengths. First, prevalence was assessed using a door-to-door survey in general population. Second, we used a standardized questionnaire previously validated in the African context. Third, trained care personnel performed the interview individually. Lastly, we performed a global assessment of sociocultural representations surrounding epilepsy in rural sub-Saharan Africa.

## 5. Conclusion

Epilepsy misconceptions are predominant in rural Central African Republic. Epilepsy is still identified as supernatural and contagious. The high prevalence of misconceptions among general population could be related to negative stereotyping of people with epilepsy promoted by disease misunderstanding and the lack of awareness campaigns in specific areas. Cultural beliefs could be associated with negative attitudes that reduced adherence to treatment and thus the increase of the treatment gap. Understanding misconceptions is an essential phase to develop culturally appropriate interventional programs in order to improve medical treatment adherence, quality of life, and to reduce stigma. Campaigns to raise awareness are needed in urban and rural population to reduce misconception and combat stigmatization.

## Funding source

No funding source was involved in the preparation of this paper or the decision to submit it for publication.

## Competing interests

None

## Acknowledgements

None.

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