

Research Article

Knowledge, Attitudes, and Behaviors of Brazzaville Residents Regarding Epilepsy

Connaissances, Attitudes et Comportements des Habitants de Brazzaville concernant l'Epilepsie

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Key words: knowledge, attitudes, epilepsy, general population, Brazzaville

ABSTRACT

Introduction. Negative socio-cultural perceptions of epilepsy, can lead to stigmatization. The aim of our study is to examine the knowledge, attitudes, and behaviors of Brazzaville residents regarding epilepsy. Methodology. This analytical cross-sectional epidemiological study was conducted from 15 May to 15 August 2023 in households in Brazzaville, Republic of Congo. The study cohort consisted of individuals aged 18 and data were collected through a questionnaire covering variables related to knowledge about epilepsy and attitudes towards patients living with epilepsy, as well as those experiencing an epileptic seizure. Results. Among the 320 participants, a low level of knowledge on epilepsy was observed (81.2%). The participants had the greatest gaps in knowledge regarding the disease itself, specifically its symptoms, aetiologies, treatment, and prognosis. The absence of previous contact with a patient living with epilepsy (OR = 2.99; p = 0.003) and the absence of previous observation of an epileptic seizure (OR = 6.36; p < 0.001) were identified as factors that influenced this knowledge. Regarding attitudes towards individuals experiencing epileptic seizures, 60.9% of cases exhibited an accepting attitude. Conversely, attitudes towards people living with epilepsy were generally positive (73.3%) and correlated with good knowledge of the social aspects of epilepsy (OR = 0.11; [0.02-0.39], p = 0.004). Positive aspects of attitude were observed in relation to intimate relationships and social interactions with patients living with epilepsy. Conclusion. Our study reveals a general lack of knowledge about epilepsy among the studied cohort. It is urgent to raise awareness to promote more effective management of epilepsy in Brazzaville.

RÉSUMÉ

Introduction. Les perceptions socioculturelles négatives de l'épilepsie peuvent conduire à la stigmatisation. L'objectif de notre étude est d'examiner les connaissances, les attitudes et les comportements des résidents de Brazzaville concernant l'épilepsie. Méthodologie. Cette étude épidémiologique analytique transversale a été menée du 15 mai au 15 août 2023 dans des ménages à Brazzaville, en République du Congo. La cohorte d'étude était composée d'individus âgés de 18 ans et les données ont été collectées à l'aide d'un questionnaire couvrant des variables liées aux connaissances sur l'épilepsie et aux attitudes envers les patients atteints d'épilepsie, ainsi que ceux qui vivent une crise épileptique. Résultats. Parmi les 320 participants, un faible niveau de connaissance sur l'épilepsie a été observé (81,2%). Les participants présentaient les plus grandes lacunes de connaissance concernant la maladie elle-même, notamment ses symptômes, étiologies, traitement et pronostic. L'absence de contact précédent avec un patient atteint d'épilepsie (OR = 2,99 ; p = 0,003) et l'absence d'observation préalable d'une crise épileptique (OR = 6,36; p < 0,001) ont été identifiés comme des facteurs influençant ces connaissances. En ce qui concerne les attitudes envers les personnes vivant une crise d'épilepsie, 60,9% des cas ont manifesté une attitude positive. En revanche, les attitudes envers les personnes atteintes d'épilepsie étaient généralement positives (73,3%) et corrélées avec une bonne connaissance des aspects sociaux de l'épilepsie (OR = 0,11 ; [0,02-0,39], p = 0,004). Des aspects positifs d'attitude ont été observés en ce qui concerne les relations intimes et les interactions sociales avec les patients atteints d'épilepsie. Conclusion. Notre étude révèle un manque général de connaissance sur l'épilepsie parmi la cohorte étudiée. Il est urgent de sensibiliser pour promouvoir une gestion plus efficace de l'épilepsie à Brazzaville.

INTRODUCTION

Epilepsy is a neurological condition that is characterized by recurrent epileptic seizures. It represents a major public health challenge, affecting around 75 million people worldwide, making it the second most common neurological disease after headache [1-5]. The prevalence of epilepsy in sub-Saharan Africa varies between 8 and 15 per thousand [5-7].

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KEY RESULTS

The aim of our study

Knowledge, attitudes, and behaviors of Brazzaville residents regarding epilepsy.

Key Results

- A low level of knowledge on epilepsy was observed (81.2%).
- 2. The absence of previous contact with a patient living with epilepsy (OR = 2.99; p = 0.003) and the absence of previous observation of an epileptic seizure (OR = 6.36; p < 0.001) were identified as factors that influenced this knowledge.

Implications for future policies and practices

It is urgent to raise awareness to promote more effective management of epilepsy in Brazzaville.

Diagnosis of epilepsy can be complex due to the various symptoms, with convulsions being the most frequently observed [1]. The management of epilepsy is crucial due to its complications, including cognitive decline that affects up to 85% of patients in Africa and a mortality rate twice as high as the general population in the region [8-13]. Negative socio-cultural perceptions of epilepsy, particularly in Africa where it is sometimes viewed as divine punishment, can lead to stigmatization. This can have a significant impact on the social life and medical care of individuals living with the condition [11, 14, 19]. Studies conducted in Brazzaville have shown differences in attitudes between students, who hold a positive view, and pupils, who are prejudiced [17, 20]. However, this study did not provide any information on the perceptions of the general population of Brazzaville. Therefore, an epidemiological study was conducted to analyze the knowledge, attitudes, and behaviors of Brazzaville residents regarding epilepsy. The aim of this study was to examine the socio-cultural perspectives surrounding epilepsy in the population of Brazzaville. Specifically, we focused on the understanding and attitudes of Brazzaville residents towards epilepsy, their reactions during an epileptic seizure and the factors associated with these perceptions and attitudes.

PATIENTS AND METHODS

The study adopted a cross-sectional and analytical approach, using the Knowledge, Attitudes and Practices methodology. The study was conducted in households in the city of Brazzaville, Republic of Congo, over a threemonth period, from 15 May to 15 August 2023. The inclusion criteria for the study were being at least 18 years old, having lived in Brazzaville for at least ten years, and having given consent to participate. The study excluded individuals with intellectual disabilities or verbal communication disorders that prevented them from answering the questionnaire, people living with epilepsy, or people working in the health sector. Participants who provided incomplete answers to the questionnaire were excluded from the study. The minimum sample size was determined using the Schwartz formula: $N = p(1-p) \times Z2$ / I2, where N is the minimum sample size, Z is the confidence level according to the normal distribution (for a 95% confidence level, Z = 1.96), p is the prevalence of individuals with inadequate knowledge of epilepsy in Brazzaville, estimated at 73% [18], and I is the margin of error, estimated at 5%. Therefore, the estimated sample size required for this study was approximately 302 individuals. The subjects were chosen through random cluster sampling. Clusters were randomly selected without replacement from the 12,509 blocks in Brazzaville city, as per the general census. The formula used to calculate the number of clusters required to reach the projected sample size was: n = N / X. Here, n represents the number of clusters to be selected to reach the sample size, N is the sample size rounded to 302, and X is the cluster size. The cluster size was calculated by dividing the number of people aged 18 and over living in Brazzaville (representing 53%, or 1,398,140) by the number of blocks, giving approximately 111.7. In order to represent the estimated sample size, approximately three blocks were required. Three blocks were randomly selected from the city of Brazzaville, specifically from the arrondissements of Makélékélé (Diata neighbourhood, block number 10), Moungali (Plateau des 15 ans neighbourhood, block number 4), and Madibou (Mbouono neighbourhood, block number 2). Subjects were exhaustively recruited from each selected household. Out of the 344 contacted subjects, 16 declined to participate in the study, resulting in a participation rate of 95% (n = 328). The survey included a total of 320 residents of Brazzaville after excluding 8 subjects. Among these participants, 33.8% resided in Makélékélé (Diata) and Madibou (Mbouono) districts, while 32.5% were from the Moungali district ("Plateau des 15 ans"). To ensure impartial responses, each participant was interviewed individually in a separate room in their home. The interviewer was not present. The data was collected through a questionnaire based on the Explanatory Model Interview Catalogue (EMIC), which is acknowledged for its cross-cultural validity. The questionnaire comprised 31 questions that covered demographics, epilepsy-related knowledge, attitudes towards individuals with epilepsy, and responses in the event of a seizure. At the end of the questionnaire, an open-ended question was asked about barriers to accessing care. The questionnaire was validated by the Health Research Ethics Committee under number 071- 40/MESRSIT/IRSSA-CERSSA on 16 November 2023.

The item's knowledge score is expressed as a percentage and determined as described by Diatewa et al **[21].** The score is presented as follows: score <50%= low knowledge; score $\ge50\%=$ good knowledge. The data were entered into Excel 2023 and analysed using R software version 4.3.2. Qualitative variables were expressed as percentages, while quantitative variables were presented as mean \pm standard deviation. To compare proportions, we used Pearson's Chi-2 test. In cases where the theoretical population was less than 5, we applied Fisher's test. To investigate the relationship between demographic variables and the knowledge and attitudes of Brazzaville residents towards epilepsy, we determined Odds Ratios (OR) and 95% confidence intervals. The significance level was set at p <0.05.

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RESULTS Demographic aspects of the study population

The majority of the participants were of Congolese nationality and Kongo ethnicity, with a higher level of education and an average socio-economic status. There were more women than men in the study population. The median age of the participants was 32 years, with an interquartile range of 30 to 34 years (**Table I**).

Table I. Data relating to the socio-demographic characteristics of the population % Characteristics Gender 140 43.8 Male Female 180 56.3 Age range (years) 18 to 24 80 25 30 25 to 35 96 36 to 64 121 37.8 65 to 80 23 7.2 **Nationality** Congolese 309 96.6 Foreign 11 3.4 Ethnic group 82.5 264 Kongo Teke 35 10.9 Swahili 4 1.3 Wolof 0.3 Level of education Primary 25 7.8 Secondary1 17 5.3

129

46

256

18

40.3

14.4

80

5.6

Family history of epilepsy was reported by 103 participants (32.2%). Furthermore, 142 respondents (44.4%) reported having been in contact with someone in a vulnerable situation during an epileptic seizure, while 178 respondents (55.6%) reported no such experience.

General knowledge about epilepsy

Secondary2

Low

High

Medium

Socio-economic level

Among the participants surveyed, 260 (81.2%) had a low level of general knowledge about epilepsy, while 60 (18.8%) had a good level. The majority, 275 (85.9%), received information about epilepsy from those around them, while 13 (4.1%) learned about it at school and 32 (10%) via audiovisual media or the internet. Regarding perceptions, 145 participants (45.3%) attributed the origin of epilepsy to natural causes, while 74 (23.1%) considered it to be of supernatural origin. Of the 320 subjects questioned, 101 participants (31.6%) did not provide a clear answer to this question. The data analysis indicates that most participants did not identify specific causal factors for epilepsy, but rather associated it with convulsions. Out of the surveyed participants, 52 (16.3%) mentioned potential triggers for epileptic seizures, while 42 (13.1%) reported none. The remaining 226 subjects (70.6%) did not provide an answer to this question (**Table** II). Regarding how epilepsy is perceived, the vast majority (86.9%) agreed that epilepsy affects all ages. A small percentage of participants felt that it only affects children (8.8%), adults (3.4%), or the elderly (0.9%).

Table II. Triggers for epileptic seizures reported by Brazzaville residents		
Triggers	N	%
Smoking	1	2
Fever	1	2
Chicken consumption	1	2
Dust	1	2
Light	2	3.8
Moon movements	2	3.8
Alcohol intake	3	5.7
Fire	3	5.7
Lack of sleep	3	5.7
Non-respect of prohibitions	4	7.7
Noise	4	7.7
Heat	4	7.7
Contact with water (rain)	4	7.7
Crowds	4	7.7
Consumption of narcotics	5	9.6
Stress	10	19.2

In terms of the severity of the condition, most participants (83.4%) were of the opinion that it was serious, while minorities (7.8%) were of the opinion that it was not serious. A small number of participants (8.8%) did not provide an answer to this question. As far as contagiousness is concerned, 73.4% of the 235 participants said that epilepsy is not contagious, while 16% thought the opposite. 10.6% did not give an answer. The modes of transmission mentioned were contact with the saliva of a person with epilepsy outside of seizures (54.9%), contact with saliva during a seizure (27.5%), body contact during a seizure (11.8%), and genetics (5.8%). Among the 320 participants, 162 (50.6%) agreed that epilepsy is a curable disease, while 82 (25.6%) disagreed and 76 (23.8%) did not respond. Regarding the management of epilepsy, the participants' responses were as follows: Of the total participants, 38 (11.9%) preferred a medical approach, 130 (40.6%) preferred a traditional approach, 134 (41.9%) preferred a combination of modern and traditional medicine and 9 (2.8%) mentioned prayer as a form of management. Nine (2.8%) participants did not provide their opinion on this subject. Figure 1 illustrates participants' responses to the possibility of a person with epilepsy (PVE) being able to attend school, work and engage in leisure activities (Figure 1). Regarding the choice of occupation for people living with epilepsy, 51.5% (n = 118) of participants believed they could work in any profession. The remaining 48.5% (n=111) mentioned specific occupations such as shopkeeper (n=46; 20.1%), doctor (n=26; 11.4%), administrator (n=28; 12.2%), carpenter (n=4; 1.7%), bricklayer (n=3; 1.3%), public transport driver (n=2; 0.9%) and soldier (n=2; 0.9%). Ninety-four subjects (29.4%) did not provide their opinion on the matter. The study identified several sports that were mentioned by participants, including football (n = 49; 50.5%), gymnastics (n = 10; 10.3%), walking (n = 28; 28.9%), running (n = 7; 7.2%), and any sport (n = 3; 3.1%). However, swimming was discouraged by 46 (45.1%) of

the 102 participants who felt that people with epilepsy should not participate in sports.

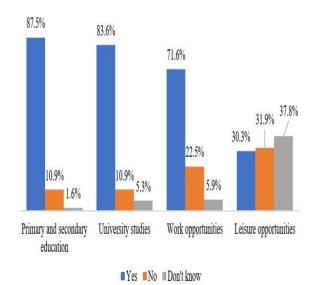


Figure 1. Comparison of responses on access to education, employment and leisure

The majority of Brazzaville residents (91.3%) believed that children with epilepsy could play with other children without epilepsy. A minority of 22 people (6.9%) disagreed. Six participants (1.9%) did not provide an answer, and 10 people (3.1%) gave no answer regarding the matter. Among the 235 participants, 225 (89.1%) thought that a person with epilepsy could get married, while 25 (7.8%) disagreed. Regarding the ability of people with epilepsy to have children, 294 (91.9%) agreed that they could, while 17 (5.3%) disagreed. Nine participants (2.8%) did not respond to this question. Among, 31.3% of the one hundred individuals reported dietary restrictions related to epilepsy. Specifically, 77% avoided poultry, 5% avoided chilli, and 4% avoided pork, cassava leaves, squash, and eggs, respectively. Additionally, 1% avoided cube, palm oil, bat, and fish, respectively.

Attitudes towards people with epilepsy

Based on the participants' responses, 257 (80.3%) had positive attitudes, while 63 (19.7%) had discriminatory attitudes. A total of 165 (51.6%) respondents were in favor and 117 (36.6%) were against when asked whether they would consider marrying an EVP. Thirty-eight (11.9%) subjects did not respond (**Figure 2**). Regarding the possibility of marrying an EVP's family member, 27 (8.4%) disagreed and 265 (82.8%) agreed. Out of the total number of subjects, 28 (8.8%) did not respond. With regard to the possibility of staying married to an EVP after the discovery of their status, 263 (82.2%) subjects were in favor, while 24 (7.5%) said they would prefer to separate from their spouse if necessary. No response was received from a total of 33 (10.3%) subjects. Among the respondents, 183 (57.2%) were of the opinion that children with EVP were possible, while 93 (29.1%) were of the opinion that children with EVP were not possible.

The main reason for not wanting to have children with EVP was fear of heredity, cited by 88 (94.6%) subjects. Seven (2.2%) subjects preferred not to have contact with an EVP for fear of witnessing a crisis, while 291 (90.9%) felt they could have normal contact with an EVP. There was no response from 22 (6.9%) subjects.

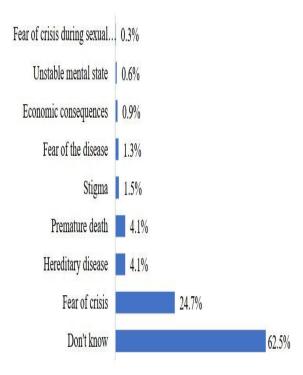


Figure 2. Reasons given by Brazzaville residents for refusing to marry an EVP

Two hundred and ninety-one participants (90.9%) agreed that it was possible to live in the same house with an EVP, while 13 people (4.1%) disagreed. Sixteen people (5.0%) did not answer. Similarly, two hundred and seventy-two individuals (85%) approved of sharing a bed with an EVP, while 28 (8.8%) disagreed. Twenty participants (6.3%) did not respond. Of the participants, 74% (n=234) agreed to share the same plate as the EVP. 20% (n=64) disagreed and 7% (n=22) did not respond. 19.1% of participants cited fear of possible contamination by the EVP's saliva as a reason for refusal. This was the most common reason for refusal. public transport driver (n=2; 0.9%) and soldier (n=2; 0.9%). Ninety-four subjects (29.4%) did not provide their opinion on the matter. The study identified several sports that were mentioned by participants, including football (n = 49; 50.5%), gymnastics (n = 10; 10.3%), walking (n = 28; 28.9%), running (n = 7; 7.2%), and any sport (n = 3; 3.1%). However, swimming was discouraged by 46 (45.1%) of the 102 participants who felt that people with epilepsy should not participate in sports. The majority of Brazzaville residents (91.3%) believed that children with epilepsy could play with other children without epilepsy. A minority of 22 people (6.9%) disagreed. Six participants (1.9%) did not provide an answer, and 10 people (3.1%) gave no answer regarding the matter. Among the 235 participants, 225 (89.1%) thought that a person with epilepsy could get married,

while 25 (7.8%) disagreed. Regarding the ability of people with epilepsy to have children, 294 (91.9%) agreed that they could, while 17 (5.3%) disagreed. Nine participants (2.8%) did not respond to this question. There was 31.3% of the one hundred individuals reported dietary restrictions related to epilepsy. Specifically, 77% avoided poultry, 5% avoided chili, and 4% avoided pork, cassava leaves, squash, and eggs, respectively. Additionally, 1% avoided cube, palm oil, bat, and fish, respectively.

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DISCUSSION

The study found that the population of Brazzaville has a low level of general knowledge about epilepsy, with only 81.2% having knowledge about the disease [18]. This lack of knowledge can be attributed to socio-cultural factors surrounding the disease, as well as a general lack of awareness. This is evidenced by the fact that 54.7% of participants could not correctly identify the origin of epilepsy. Only 10% of participants said they had learned about epilepsy through the media. In addition, more than half of the participants had no previous experience of people with epilepsy. This highlights the importance of personal contact in gaining knowledge. The study found that having met someone with epilepsy (OR=5.18;

p<0.001) and having witnessed an epileptic seizure (OR=6.91; p<0.001) were associated with greater understanding. These findings are in line with studies in the Central African Republic and Benin, where the population had previously been exposed to epileptic seizures [15, 26]. Only 18.8% of the population of Brazzaville showed a good level of knowledge about epilepsy. 46.6% of the participants had a high level of education. The impact of education on general knowledge has been demonstrated, provided that awareness is raised. In a previous study in Brazzaville, 26.9% of students had good knowledge [18]. In contrast, in Benin, only 6.1% of the semi-urban population had good knowledge [27]. These findings highlight the importance of education in improving knowledge. The local terms used in this study to describe epilepsy refer to the symptoms of generalized tonic-clonic seizures, which are the most common form of the condition due to their startling nature. The meanings attributed to them reflect concepts that describe epilepsy as a disease that causes jerky movements, like a bird, or as a disease that causes a sudden fall [16, 18, 28, 29, 31]. Dietary restrictions are imposed on people living with epilepsy (PVE) due to cultural interpretations. For example, the consumption of poultry or fish such as eel is forbidden. This is because generalised clonic movements are associated with convulsions from slaughtered birds or suffocated fish. It is believed that eating these foods can increase the frequency and duration of epileptic seizures. In this study, consistent with previous research [15, 84, 86], 83.4% of participants considered epilepsy to be a serious illness. Reasons given included the risk of accidents during seizures such as burning, drowning and head trauma [15,28]. In addition, 15% of participants in our study believed that epilepsy was contagious, mainly through saliva as a vector of transmission. For example, in Côte d'Ivoire, 14% of relatives of people with epilepsy shared this belief [30]. In a study conducted among students, up to 90% were affected by fear of getting infected [16]. Approximately one third of participants in our study believed that epilepsy was incurable, which is higher than reported elsewhere [13]. This perception reflects the challenges of epilepsy management in Africa, including delays in diagnosis and difficulties in accessing effective treatments, particularly in rural areas. In response, many participants combine different therapeutic approaches, including modern medicine, traditional medicine and religious practices, a trend that has been observed in other studies conducted in Africa [17,29]. The use of nonconventional therapies may stem from beliefs in a supernatural origin of epilepsy, which is shared by about a quarter of the participants in the study and has been observed in other populations [73,26]. These data demonstrate that socio-cultural factors continue to influence the management of epilepsy in Africa, regardless of location, educational level or professional status, and have important implications for interacting with people living with epilepsy. The study found that the general population had positive attitudes towards people with epilepsy (PWEs), with 80.3% of participants expressing tolerance and sympathy towards these

individuals. This finding is consistent with a similar observation in Nigeria, as reported by Kabir et al [33], where the majority of respondents were sympathetic towards PWEs. Although the expression of positive attitudes towards epilepsy is encouraging, it is important to continue to raise awareness of the condition. Our study found that 19.7% of participants still held stigmatising attitudes towards epilepsy. Additionally, our analysis revealed that the expression of positive attitudes was associated with the participants' level of knowledge (OR=0.11; p=0.004). Most participants in our study expressed support for schooling for people living with epilepsy (PVE). However, attitudes towards epilepsy vary widely in Africa, with Mbelesso et al [34] finding 82.3% in favour in schools in central Africa, while Adoukonou et al [14] found 64.4% against in rural Benin. In addition, Haydar et al [26] found that almost 80.7% of Sudanese primary and secondary school teachers believed that children with epilepsy should not attend school. Regarding EVPs practising a profession, most participants in our study supported this possibility. In particular, they recommended administrative and commercial positions. A study in Côte d'Ivoire found that some students believed that EVPs could not practice all professions, suggesting positions of responsibility such as company manager or village chief [16]. Only 30.3% of participants in our study agreed that EVPs should participate in physical activities, especially sports. Overcoming reluctance is crucial, as physical activity is beneficial for children with epilepsy without additional disability, and the risk of accidents during sports activities is very low [76,36,37]. Studies have shown that people with epilepsy are often excluded from society and even from their own families due to stigma. Social exclusion can lead to the desocialisation and marginalisation of people with epilepsy, as exemplified by being refused to eat or socialise with them [14, 17, 18, 26, 27, 29, 38]. To promote the social integration of EVPs, it is imperative to combat these behaviors. Regarding marriage and reproduction, although most study participants acknowledged that people with epilepsy can marry and have children, a significant proportion expressed reluctance, particularly at the idea of marrying someone with epilepsy. This stigma surrounding marriage to a person with epilepsy has been observed in several studies and may result in social isolation [14, 15, 34, 39, 40]. Finally, if someone has an epileptic seizure, they should be taken to hospital immediately. This is also recommended by teachers and health professionals [39]. However, some inappropriate practices, such as refusing to touch the person having a seizure or running away, may be motivated by fear due to the dramatic nature of the tonic-clonic seizure and beliefs about the contagiousness of epilepsy [14,24,38,41,42].

CONCLUSION

The study revealed a general lack of understanding regarding epilepsy, especially regarding its medical aspects. Knowledge gaps were significantly associated with limited experience of epilepsy. While most attitudes towards people with epilepsy were positive, there were

some cases of prejudiced expectations. However, day-today interactions with people with epilepsy were generally positive, highlighting the importance of adequate social skills. To improve the overall management of epilepsy in Brazzaville, these findings highlight the need for information and awareness campaigns.

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