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Abstract:

Introduction: Sociocultural representations in Africa remain a limitation in the care, integration and insertion of people living with epilepsy (PWE). African youth is an ideal target for advocacy policies.

Aim: To analyse knowledge about epilepsy and sociocultural considerations and attitudes towards the PWE in the student population of Brazzaville.

Population and methods: A prospective descriptive study was conducted for two months in Marien Ngouabi University of Brazzaville and two accredited private institutions of higher education. It involved 264 students, to whom an approved questionnaire was submitted.

Results: The word "epilepsy" was known to all respondents; their entourage was the main source of information. It was considered frequent in 25.8% and of natural origin in 62.9%. It was designated as severe in 95.5%, contagious in 14%, and curable in 77.3%. The initial treatment was prayer in 48% and traditional medicine in 64.2% of people. The main factors triggering seizures were stress (37.3%), noise (17.5%) and alcohol intake (11.9%). Contact with a PWE was considered harmful in 21.2%. PWE could be educated, practice a leisure activity, sport, and job in respectively 92%, 96.6%, 70.1% and 90.9%. PWE could be married or procreated in 97% and 98.5% respectively. The main actions recommended for a seizure were the removal of all contact (29.5%) and security (20.5%).

Conclusion: Although the sociocultural representations of epilepsy in our subjects are rather positive, there are still popular beliefs in this educated layer that are subject to the stigmatization and social disability of PWE.

Keywords: Brazzaville – Epilepsy- Sociocultural representations- Students

Résumé :

Introduction : Les représentations socioculturelles en Afrique restent une limite dans la prise en charge, l'intégration et l'insertion des personnes vivant avec l'épilepsie (PWE). La jeunesse africaine est une cible idéale pour les politiques de plaidoyer.

Objectif : Analyser les connaissances sur l'épilepsie et les considérations et attitudes socioculturelles envers le PWE dans la population étudiante de Brazzaville.

Patients et méthodes : Une étude descriptive prospective a été menée pendant deux mois à l'Université Marien Ngouabi de Brazzaville et dans deux établissements privés d'enseigne-

ment supérieur agréés. Elle a concerné 264 étudiants, auxquels un questionnaire validé a été soumis.

Résultats : Le mot « épilepsie » était connu de tous les répondants ; leur entourage était la principale source d'information. Elle était considérée comme fréquente dans 25,8% et d'origine naturelle dans 62,9%. Elle a été désignée comme sévère dans 95,5%, contagieuse dans 14% et curable dans 77,3%. Le traitement initial était la prière dans 48% des cas et la médecine traditionnelle dans 64,2% des personnes. Les principaux facteurs déclenchant les crises étaient le stress (37,3%), le bruit (17,5%) et la consommation d'alcool (11,9%). Le contact avec un PWE était considéré comme nocif dans 21,2%. Les PWE pouvaient être scolarisés, pratiquer une activité de loisir, un sport et un travail dans respectivement 92%, 96,6%, 70,1% et 90,9%. Les PWE pouvaient être mariés ou procréer dans 97% et 98,5% respectivement. Les principales actions recommandées pour une saisie étaient la suppression de tout contact (29,5%) et la sécurité (20,5%).

Conclusion : Bien que les représentations socioculturelles de l'épilepsie chez nos sujets soient plutôt positives, il existe encore des croyances populaires dans cette couche éduquée qui sont sujettes à la stigmatisation et au handicap social des PWE.

Mots clés : Brazzaville – Epilepsie- Etudiants -Représentations socioculturelles

Introduction:

Epilepsy is a neurological disorder characterized by a predisposition to generate seizures and its neurobiological, cognitive, psychological and social consequences [1, 2].

Epilepsy affects nearly 50 million people worldwide, 80% of whom live in low- and middle-income countries [3]. In sub-Saharan Africa, the prevalence of epilepsy is about 74% [4]. The socio-cultural representations of epilepsy in Africa, considered as a sacred evil or a curse, as well as the stigmatization of those affected, persist to this date and leads to the use of traditional healers [5-7]. These different considerations remain the main obstacle to the proper management of people living with epilepsy (PWE), with nearly 70% of them without access to adequate therapies, while in developed countries, 70% of PWE are controlled [3].

In Congo, few studies have been conducted on the socio-cultural representations of epilepsy. Considering the relative youth of Congolese population, our interest was focused particularly on the student population. Indeed, students represent an ideal interface between knowledge rational acquired during their study, and socio-cultural and religious beliefs through their

belonging to a given family and social environment. These are future opinion leaders and heads of family. Identifying and analysing knowledge about epilepsy among them would certainly be helpful to change misconceptions, prejudices, stigmatizing attitudes and practices that are harmful to the PWE. This study was conducted with the aim of determining the socio-cultural representations of epilepsy in the student population of Brazzaville; including knowledge about epilepsy and socio-cultural considerations and attitudes towards the PWE.

1.Population and methods

It was a descriptive prospective study carried out over a two-month period from May 7 to July 7, 2017, in the eleven public institutions of Marien Ngouabi (UMNG) university of Brazzaville and two private higher institutions of Brazzaville accredited by the Congolese state. The Congolese population living in Brazzaville comes from eleven departments of the country, by a phenomenon of rural exodus of economic and educational reasons. Moreover, Marien Ngouabi University (UMNG) of Brazzaville is the only public university of Congo. Created in 1971, it now has eleven institutions conducting teaching and research activities. Of the 31 private higher education institutions in the city of Brazzaville, only two have the final approval of the regulatory authorities. We included in this study students of any of the above-mentioned higher education institutions, whether or not resident in Brazzaville, regardless of their nationality, and having signed their informed consent to participate in the study. Those whose interview was interrupted for any reason were excluded from the study. The selection of the study population was by simple random sampling. The subjects were divided equally by three options (science and technique, literature, sport) and education level (first cycle versus second and third cycles). Sciences and technique included the studies of mathematics, physical sciences, agronomy, accountancy, biology, chemistry, geology, medicine, nursing, biomedical sciences, public health; literature option consisted of studies in French, foreign languages, philosophy, sociology, social administration, law; and sport option comprised sports and physical education studies. The minimum size of our sample was estimated at 214 subjects.

After recording the sociodemographic features of students (age, sex, nationality, ethnicity, religion, option and level of study), they were questioned on their general knowledge of epilepsy and on general and personal socio-cultural considerations and attitudes towards the PWE. Data collection was based on an interview guide based on the Explanatory Model Interview Catalog (EMIC), a cross-cultural and adaptable tool depending on the environment and the disease studied [8-10]. The interview was semi-directed and each subject was individually maintained and isolated during his break. The questionnaire consisted of simple choice, multiple choice, and free and short answer questions. A preliminary survey was conducted the month before the study and involved 15 subjects to assess the comprehension, the relevance and the homogeneity of the proposed questions.

Statistical analysis

The data was backed up in Microsoft Excel 2007 and analysed by SPSS 20.0 for Mac. Quantitative variable, age of subjects, was presented in median and interquartile range because of its non-Gaussian distribution. The rest of the qualitative variables were expressed in number and frequency. This study has been approved by the UMNG authorities.

2.Results

2.1.Socio-demographic features

Of the 280 respondents initially included, 16 were excluded for incomplete interview. The final number of respondents selected was 264. The median age of the people was 24 years with an interquartile range between 22 and 28 years. There were 167 (63.3%) men and 97 (36.7%) women (sex ratio of 1.7), and 259 (98.1%) students were congolese. The major ethnic groups were the Kongo group (n = 163, 62.9%), the Téké group (n = 51, 19.7%) and the Ngala group (n = 45; 17.4%). Among the five foreigners, three belonged to the Téké group and one to the Fang ethnic group from Gabon, one to the Ngambay ethnic group from Chad. The Christian religion was practiced by 249 (94.3%) people.

2.2.General knowledge about epilepsy

2.2.1.Knowledge of the word "epilepsy", denominations, meanings and interdictions

All students had knowledge of the word "epilepsy". The sources of information were entourage for 243 (92%), school for 12 (4.5%), audio-visual media for seven (2.7%), and a seminar for two (0.8%). The denominations of the word "epilepsy" in the traditional language of the three major ethnic groups were known by all, as were the taboos (Table 1).

In the two vernacular languages spoken in Brazzaville, Lingala and Kitûba, the consecrated expression was "malade ya ndêké" meaning "what makes people waving like a bird being slaughtered". Moreover, in Kitûba, a second expression was "nzietâ", meaning "what makes you dizzy". A foreign denomination has been reported from the Ngambay ethnic group of Chadian origin; "claye" meaning "what has changing manifestations" like the chameleon.

Table 1. Denominations of the word «epilepsy» in traditional languages, its meanings and prohibitions.

Denominations	Meanings	Prohibited
Kongo group		Poultry, kôkô (Gnetum africanum), frozen drinks, peas, horse mackerel head, eels, beans, pork, alcohol, sour vegetables, saka-saka (crushed cassava leaves), sexual intercourse.
Mpoukâ	« What make you suddenly fall »	
Mfoua	« Half dead »	
Sissou	« What makes the eyes roll back »	
Téké group		Poultry, frozen drinks, horse mackerel head, catfish.
Itsoua	« What is unpredictable »	
Sissi	« What makes you fall »	
Tsike	-	
Otinga	« What makes it tick like a suffocating fish out of the water »	
Ession	-	
Ngala group		Poultry, catfish, alcohol, tobacco, saka-saka.
Otinga	« What makes it tick like a suffocating fish out of the water »	

2.2.2.Perceived frequency, origin and causes of epilepsy

Epilepsy was considered a frequent and rare by 69 (25.8%) and 183 (69.3%) students respectively. When asked about the natural or supernatural origin of epilepsy, 166 (62, 9%) and 24 (9.1%) respectively thought it was a natural disease and a

supernatural disease related to witchcraft. Sixty-nine (26.1%) students thought it could be both natural and supernatural and five (1.9%) were unanswered. Of the medical causes of epilepsy, it was a neurological disease for 171 (64.6%) students, a psychiatric condition related to madness for 61 (23.1%) and 32 (12.3%) did not answer. The perceived causes of epilepsy by students are shown in Figure 1.

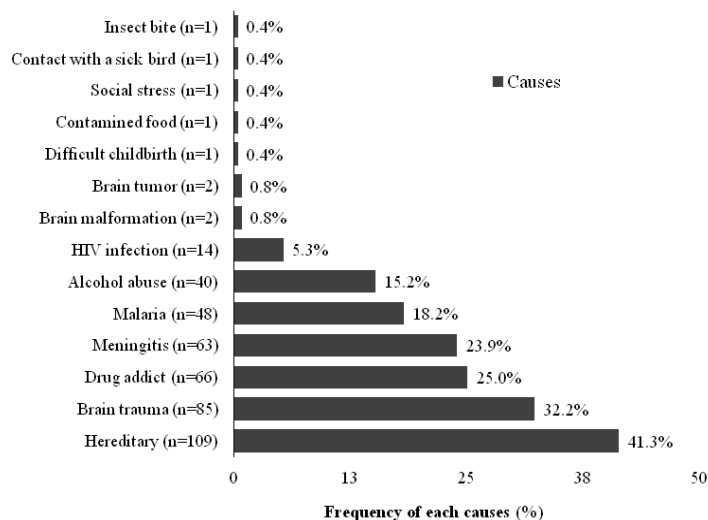


Figure 1. Perceived causes of Epilepsy by respondents (HIV: Human Immunodeficiency Virus).

2.2.3. Severity, contagiousness, chronicity and curability of epilepsy

Epilepsy was recognized as a severe disease by 252 (95.5%) students and benign by seven (2.7%). Five (1.8%) students did not answer. The reasons given for the severity of epilepsy are presented in Table 2.

Table 2. Evidence of the Perceived Severity of Epilepsy by Subjects (n = 252).

Reasons	n	%
Drowning, burning by fire	135	53.6
Road traffic accident	32	12.7
Long-term treatment	16	6.3
Sequelae of psychiatric disorders	13	5.2
Stigmatization	13	5.2
Loss of consciousness	11	4.4
Physical disability	10	4.0
Cognitive dysfunction	5	1.9
Restriction in daily life activities	4	2.0
Lack of oxygen in the brain	3	1.2
Loss of memory	3	1.2
Unknown	19	7.5

Most of the students (n=211, 79.9%) affirmed the non-contagiousness of epilepsy. Thirty-seven (14%) people indicated that it was contagious and 16 (6.1%) did not answer. The means of contamination indicated were; contact with the saliva of a PWE during seizures (n = 31, 83.8%), body contact with PWE (n = 10, 27.0%), sexual intercourse with PWE (n = 2; 5.4%) and contact with a bewitched hen (n = 1, 2.7%). Epilepsy was considered as a chronic disease by 156 (59%) stu-

dents and 73 (27.7%) considered it as a non-chronic disease. Thirty-two (13.3%) students were unanswered. Epilepsy was treatable for 204 (77.3%) students and its non-treatable for 34 (12.9%). Twenty-six (9.8%) students did not answer. The different treatments were modern medicine (n = 123, 60.3%), traditional medicine (n = 131, 64.2%), and prayer (n = 98, 48.0%). The therapeutic itinerary of the PWE suggested by the students are shown in Figure 2.

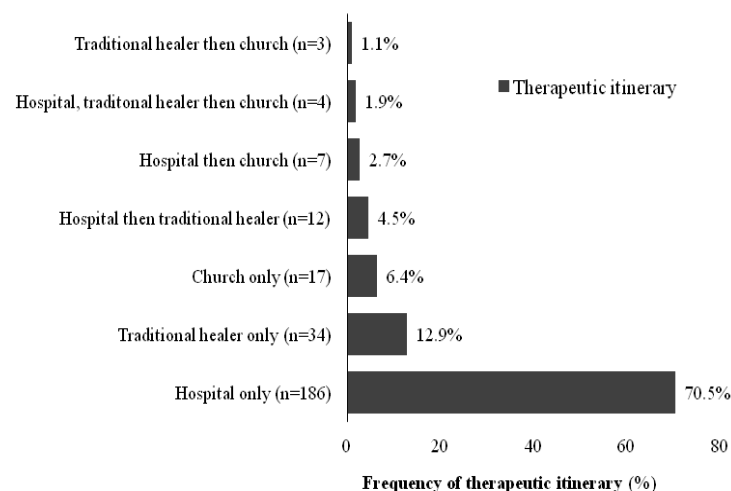


Figure 2. Therapeutic itinerary chosen as first-line for the management of people living with epilepsy (n=264).

2.2.4. Manifestations and factors triggering a seizure

Two hundred and forty-two (91.7%) students have already seen a seizure. They described mainly the generalized tonic-clonic seizure (n = 225, 85.2%); drooling (60.2%), falling (55.3%), loss of consciousness (32.2%), eyes rolling up (20.1%), stridor (4.9%), tongue bite (3.8%), loss urine (3%) and moan (2.7%). The other possible manifestations of seizure indicated by the students, except those related to the generalized tonic-clonic seizures (GTCS) were: cognitive disorders (n = 6, 2.3%), hallucinations (n = 4, 1.5%), stiffening of the whole body (n = 3, 1.1%), shaking of one half of the body (n = 3, 1.1%), agitation (n = 2, 0.8%), absence (n = 1, 0.4%), aggressiveness (n = 1, 0.4%), dyspnoea (n = 1, 0.4%). Triggering factors reported by 126 students (47.7%) are shown in Figure 3.

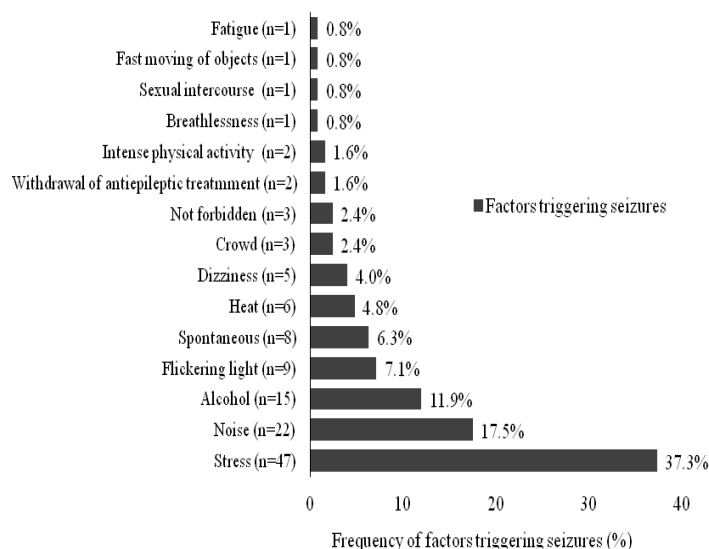


Figure 3. Factors triggering seizures

2.3.Sociocultural considerations and attitudes towards PWE.

2.3.1.Contact, circumstances of meeting and perceptions of PWE.

Two hundred and forty-two (91.7%) students had reported having already met a PWE and 22 (8.3%) had never seen a PWE. These circumstances of meeting with PWE were, a passer-by (28.5%), a neighbour (23.6%), a close relative (21.1%), a friend (12.4%), or a study colleague (10.7%).

Fifty-six (21.2%) students thought that contact with an PWE would be harmful for others and for 207 (78.4%), the contact would be safe. The exclusion of PWE was recommended by 11 (4.2%) students and 251 (95.1%) thought it was possible to maintain normal contact with PWE. Two (0.8%) were unanswered. Six (2.3%) students reported not being able to visit a PWE and 257 (97.3%) were able to visit. Sharing a meal on the same dish as a PWE was disproved by 39 (14.8%) students and approved by 221 (83.7%).

On the consideration of PWE in society, for 88 (33.3%) students, PWE would be stigmatized and for 173 (65.5%), PWE would not be stigmatized.

2.3.2.School and higher education, sport and leisure activities, job.

Scholarship of PWE was approved by 243 (92%) students and rejected by 21 (8%). Access to university was approved by 239 (90.5%) students and 20 (7.6%) thought that it was impossible.

About leisure's activities of PWE, 255 (96.6%) students approved it and eight (3%) were opposed. The practice of a sport was approved by 185 (70.1%) students and 65 (24.6%) were against. Recommended sports disciplines were football (39.8%), gymnastics (43.9%) and cycling (27.9%). Boxing and swimming were recommended respectively by 202 (76.5%) and 205 (77.7%) students.

For 240 (90.9%) respondents, PWE could get a job and 21 (8%) were against. The type of trade not recommended among the trades proposed were car driving (84.8%), surgery (75%), masonry (65.2%), medicine (51.5%), office (12.8%) and trading (15.9%). The rest of the respondents were unanswered.

2.3.3. Marriage and procreation

Two hundred and fifty-six (97%) respondents agreed that a PWE could get married, six (2.3%) were against. When asked if they can marry someone living with epilepsy, 155 (58.7%) were supportive of this possibility, 100 (37.9%) against and nine (3.4%) unanswered. The reasons for refusing to marry a PWE are shown in Figure 4. If they discovered epilepsy during pregnancy, 242 (91.7%) subjects reported that will stay married and support their spouse, while sixteen (6.1%) will divorce and six (2.3%) were unanswered. Seventeen (6.4%) subjects reported that they could not marry a relative of a PWE, while 243 (92%) reported this possibility and two (1.5%) unanswered. Ability of PWE to procreate was approved by 260 (98.5%) respondents, while four (1.5%) were against.

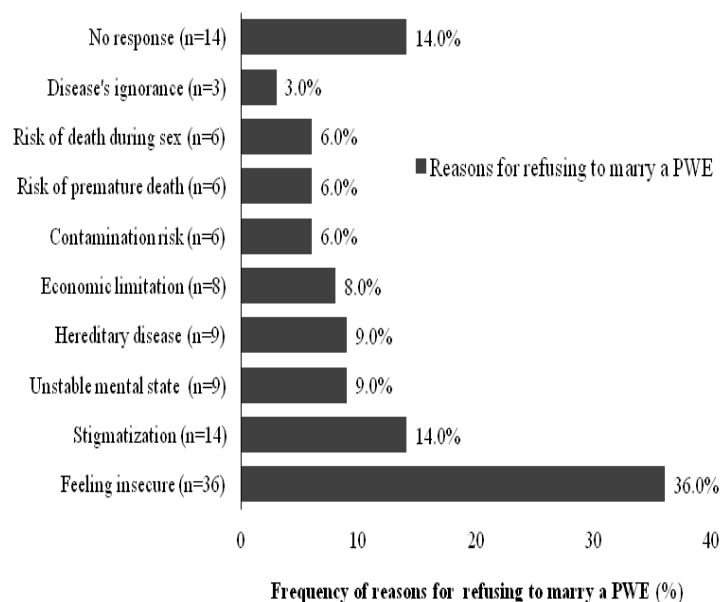


Figure 4. Reasons for refusing to marry a people living with epilepsy (PWE)

2.3.4.Action to perform in case of seizure

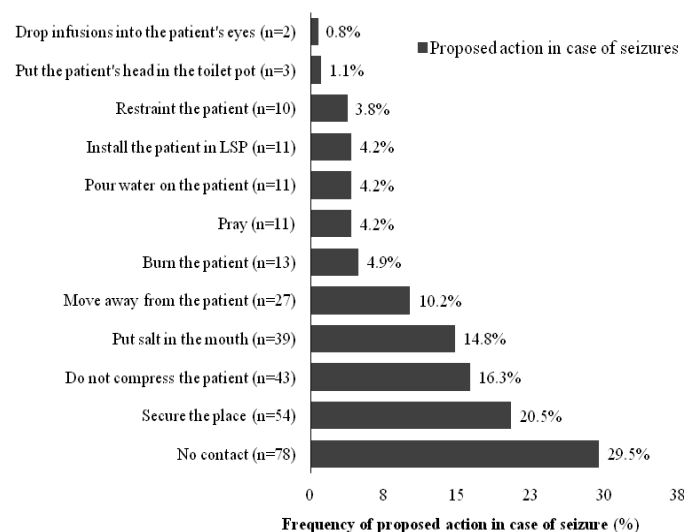


Figure 5. Proposed action in case of seizure

3.Discussion

3.1.General knowledge about epilepsy

3.1.1.Knowledge of the word «epilepsy», denominations, meanings and interdictions.

The word “epilepsy” as a “disease” is known by many people in Africa; all the subjects in our study were aware of it and most had already observed a seizure. Assi et al. [6], in Ivory Coast, reported that 85.7% of students surveyed had already seen a seizure. Also, in rural population of Benin, all had observed seizures at least once [7]. The high percentage of people who have already seen a seizure maybe explained by a higher prevalence of epilepsy in our environment, requiring general population prevalence studies. The main source of information on epilepsy was the entourage in our study. This situation confirms the lack of contribution of the official channels of communication in epilepsy sensitization campaign, which can lead to the transmission of erroneous information.

Several denominations of epilepsy in different traditional languages have been identified. Each of them relates mainly to

the manifestations of GTCS, with meanings more or less similar to those reported in African literature [11-13]. Food prohibitions relate more often to the meaning given to the disease or its alleged origin «mystical» [11, 13]. For example, it was forbidden to eat all kinds of hen or fish because, in people belief, seizures reflected the movements that a hen makes when it is slaughtered or suffocating fish out of the water.

3.1.2.Frequency, origins and perceived causes of epilepsy

The natural origin of epilepsy was also reported in 47% of Ivorian students (6). Main aetiologies incriminated were heredity, head trauma and drug abuse, as reported in several studies [7, 14-16].

Concerning the belief in the supernatural origin of epilepsy as witchcraft, in Ivory Coast, 46% of people accompanying PWE at consultation reported supernatural origin of epilepsy, of which 52% had a university level, as well as 28.8% school students in Central African Republic and 16.3% in urban areas in Nigeria and Mali [13, 15, 17, 18]. These data show the deep attachment in traditional beliefs about epilepsy in Africa, despite the relative access to education, and therefore, their potential negative impact on PWE. In addition, the consideration of epilepsy as a psychiatric disease like madness, lead to erroneous and stigmatizing idea, but frequently reported [13, 18, 19]. The personality of PWE who likely have a higher risk than the general population to develop psychiatric conditions such as depression, anxiety or psychosis can be an explication [20-24].

3.1.3.Severity, contagiousness, chronicity and curability of epilepsy

The consideration of epilepsy as a serious condition was also reported by Yapo et al., Milogo et al., and Assi et al. [6, 13, 25]. The reasons justifying this severity are similar to those already reported, especially onset of accidents during seizures: burns, drowning, brain trauma [6, 13, 16, 25]. In this study, few students also incriminated, stigmatization and the risk of developing psychiatric disorders.

The contagiousness of epilepsy reported at a low frequency in our study, was also reported by Yapo et al. [13]. This can be explained by the familiarity with the disease, because the majority of the subjects had already been in contact with a PWE. The curability of epilepsy was affirmed by 77% of students in our study, while Kossivi et al. [5] found that 78.33% of rural health workers reported that epilepsy is incurable. Indeed, the response of this health workers would reflect the difficulty of adequately taking care of PWE in rural areas. In our study, the treatment methods reported were a combination of modern medicine, traditional medicine and prayer. However, the main therapeutic route chosen was hospital. This choice was also recommended by teachers and medical staff in Gabon [26].

3.1.4.Manifestations and triggers of seizure

The description of the GTCS made in our study was similar to those reported by ivorian students and elsewhere [6, 17]. In a study in the rural area of Northern Benin, the description of seizure was more approximate [7]. Milogo and Traoré [25], in Burkina Faso, in school student, found that only 7% knew at least two signs of epilepsy; highlighting the interest to educate school students and the less educated people about epilepsy. The factors triggering a seizure were not known to more than half of the subjects, although a large proportion had already seen a seizure.

The main factors mentioned were stress, noise and alcohol

intake. Indeed, stress is recognized as a trigger for seizures, supported by experimental studies reporting during stress, the release of proconvulsive substances such as corticotrophin releasing hormone, glucocorticoids and sulphated neurosteroids [20, 27, 28].

3.2.Cultural representations of people living with epilepsy

3.2.1.Contact, circumstances of meeting and relationship

Exclusion of PWEs from the society or their own family is not only the fact of traditional African societies. In France, one on five PWE claims to be avoided by others [29]. Adotevi and Stephany [30], in Benin, highlighted the isolation of PWE by the community, even placing in a chicken coop and forbidding to share a meal with the family because of fear of contamination. This attitude could result from revulsion and rejection inspired by seizures [31]. These considerations are certainly responsible for the difficulties in social integration and educational and professional insertion of PWEs [5].

3.2.2.School and higher education

The majority of students in our study thought that an PWE could be schooled. However, for those who proscribed schooling of PWE, the reasons are avoiding humiliation of a seizure out-door, and learning disabilities. In most Knowledge Attitude Practices (KAP) studies on epilepsy in Africa, the question of schooling of the PWEs is reported differently according to the type of population [6, 7, 18, 32].

3.2.3.Practice of physical or leisure activities

For prohibition of the practice of sport, this restrictive discriminatory attitude as well encouraged by teachers and doctors could generate behavioural problems and integration difficulties [33]. Physical activities of child or adolescent living with epilepsy with no additional disabilities should be encouraged without restriction. The risks of cycling are discussed according to the context (city or countryside, etc.) and the type of epilepsy (photosensitivity) [34]. In Croatia and Hong Kong, 6.7% and 6% of respondents respectively, would not let their children have fun with children living with epilepsy, while only 3% of the students shared this opinion in our study [14, 35]. The subjects wrongly thought that these children with epilepsy would be more fragile than the others or even feared the risk of contamination for their children.

3.2.4.Professional activities

A large number of respondents (90.9%) in our study thought that PWEs could have a job. Recommended activities were office work and business. However, risky activities were public transport (84.8%) and masonry (65.2%), which should not be recommended. In Ivory Coast, 50.7% of students thought that PWEs could not practice any profession, so that jobs like company manager, village chief or generation leader, should be prohibited for them [6]. Evaluation of PWE's school and professional integration in our setting is necessary not only to determine the extent of social difficulties but also to apprehend the measures necessary to modify these considerations.

3.2.5.Marriage and procreation

Possibility of getting married and a childbirth was approved by a large proportion of respondents. The same observation was reported for 90% of students in Ivory Coast and 80.2% of students in Central African Republic [6, 18]. However, 37.9% of our respondents did not accept the idea of getting married with a PWE because they do not feel directly concerned. Stigmati-

zing attitude against marriage has been reported elsewhere [5, 14, 36]. Also, some of our respondents, in a small proportion, said they could not marry a family member of a PWE or could divorce if they discovered that their spouse is a PWE.

3.2.6. Gestures to perform in the face of a seizure

Recommended attitudes when facing a seizure were more often harmful, going from the absence of any contact, to the fact of burning the foot and run. The practice of burning the foot has also been reported in Togo [5]. The particularity noted in our study was to put the head of the victim in the toilet pot (odour will awake the patient), or introduce salt into the mouth.

Conclusion

Although mostly know the word «epilepsy», its natural origin, its clinical manifestations and the adequate therapeutic route; it persists in these students, certainly educated, a deep ancestral and popular beliefs, often erroneous, harmful, stigmatizing or even discriminatory towards the PWEs. This shows the lesser involvement of official channels of communication in raising awareness about epilepsy, in this case the audio-visual media and education. In order to address this issue, a general population study would better define the sociocultural determinants involved in the popular conception of epilepsy for more targeted interventions. Also, a study on integration and socio-professional and school integration of PWEs would help to better define their place in our society.

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