Perception of Epilepsy in Lubumbashi, Democratic Republic of Congo: Findings from Public Opinion Poll

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Abstract

Introduction: In Sub-Saharan Africa, the disease is generally considered a bad spell cast by sorcerers, the sick person or a family curse. In the religious world, they are regarded as divine punishment and can only be cured by prayers and supplications. The aim of this study is to raise the impression of people’s perception of epilepsy and its treatment.

Methods: We conducted a cross-sectional study, and a questionnaire was sent to the inhabitants of the city of Lubumbashi, all levels, social and education, and religion combined. The duration of the investigation was 5 months, 885 people were interviewed. 45.5% of our respondents are female against 54.5% male (n=885) sex ratio is 1:2; 94.70% of respondents have a high school or higher education. All respondents believe in God. With 82.67% of Christians. All have heard of epilepsy, 28.8% in school; 21.8% in mental health centers; but only 49.4% have heard about it on radio and television. 61.8% of our respondents refused to marry a person with epilepsy, 18.3% have attended a seizure, only 33.1% of respondents believe that epilepsy can be treated by the neurologist as 73.0% think that epilepsy is a mystical-religious disease.

Conclusion: From this survey, we hold that 73.0% think that epilepsy is a mystical-religieuse disease. Given the fact that 94.73% of respondents have a high level of education, one would expect that the perception of epilepsy is more scientific than metaphysical.

Keywords: Epilepsy, Perception, Community

Introduction

Epilepsy is one of the major brain disorders worldwide and should be considered a health care priority in Africa. It is triggered by abnormal electrical activity in the brain resulting in an involuntary change in body movement, function, sensation, awareness and behavior. The condition is characterized by repeated seizures or “fits” as they are commonly called. These take many forms ranging from the shortest lapse of attention to severe and frequent convulsions. Yet, epilepsy continues to take its toll among our people causing impaired physical, psychological and social functioning of those affected, and equally serious psychological, social and economic consequences for their families [1].

Epilepsy is the first chronic neurological disorder by the impact they affect 50 million people, including 10 million in Africa.

The World Health Organization (WHO) estimates that about 50 million the number of epileptic worldwide in 1998 [2].

It is considered that 3-10 million Africans have epilepsy and that 80% of them are deprived of care (WHO 2000). Epilepsy is real public health problem in Africa [3].

They are of all ages, but especially within childhood, adolescence and the ageing population. Epilepsy provides the clearest example of a neurological disorder for which effective and cost efficient treatment is available. Recent studies both in the developing and in the developed world revealed that if properly treated up to 70% of people with this condition could live productive and fulfilling lives, free from seizures [4].

Epilepsy across civilizations and centuries

In ancient times, epilepsy then called "sacred disease" was considered a witness to the wrath of the gods. She had already
caught the attention of doctors and Hippocrates who lived 400 years before Christ; who had dedicated 3% of his writings, therefore emphasized its organic nature [5].

In the middle ages, the disease had been treated as a demonic possession. This approach to disease was favored by the spread of the monotheistic religions, the devil and the moon were implicated as responsible for the occurrence of certain crises [5].

Considered infectious, epileptics were marginalized from society. At the time of rebirth and enlightenment (XVIII), it was considered epilepsy as connected to engineering, and any exceptional person was suspected epilepsy. The late eighteenth century saw a scientific appear realistic approach on epilepsy [6].

During the nineteenth century, significant progress had been made on terminology and neuropathology of epilepsy that were very gradually separate mental illness especially of hysteria.

Towards the end of the century it was clear that there are different forms of epilepsy; some are idiopathic, other related localized unresectable brain injury in some cases [6].

During the twentieth century, thanks to the development of medical technology that is to say, therapeutic and diagnostic advances (the international classification of seizures and epileptic syndromes), new advances in the knowledge of epilepsy were performed [6].

African image of epilepsy

In Africa mosaic of peoples with diverse cultures, epilepsy is a disease of the individual but also of society. It has always existed and would report to the mystical, mythical and its cause of metaphysics: the geniuses of the bush, throw out, "work" of an enemy or a punishment of an ancestor through improper conduct, etc. [7].

This procession of prejudice transmitted from generation to generation dedicated the rejection of the epileptic, common to all African cultures. Indeed, the epileptic child has no right to education because very often hidden by the family; it is excluded recreational activities, cannot get married because of the risk of contamination, it is the plan of work a primary disqualified; This poses serious problems regarding the social integration of the epileptic in Africa [8,9].

Despite the importance of these factors, our study aims: to know the perception by the population of Lubumbashi epilepsy and their attitude toward the sick.

Few studies have been conducted on the knowledge and attitude of the people on epilepsy in DR Congo. Our study has interest to document the void on epilepsy in our country.

Methodology

This work is a survey conducted in the city of Lubumbashi; November 14, 2013 to February 23, 2014 is a period of 4 months. All municipalities in the city of Lubumbashi have been covered by our investigators, only adults 18 years of age participated in the study. Entire neighbor hoods were subjected to this survey and our sampling was done in snowball house after house. A tested questionnaire composed of 2 parts was submitted to respondents, the first shows socio-demographic data, age, gender, level of education, residence and marital status, the second part contains 12 questions about it ranging from knowledge of the disease itself to the environmental implications thereof.

All these issues were linked to educational level, in following the religion of the respondents.

We had to investigate 903 people, only 885 questionnaires were selected for their completeness and clarity of answers.

The informed consent of each respondent was obtained before the study, and our investigators are reassured understanding of the questionnaire, it has been done in French only, a local language translation was made when appropriate.

Results

Our study was conducted in the city of Lubumbashi on a total of 903 people who have been tested questionnaire including replies from 885 respondents were crossed by religion of the respondent or his level of study.

The male was found to be 54.50%, with a sex ratio M/F 1.2. 48.9% of respondents are university level against 45.8 secondary level; small craft is predominant is to say, professional or 23.20%, the municipality of Kampemba alone had 33.8% of respondents.

39.7% of respondents believe that epilepsy is a form of witchcraft curse and 33.3%, 83.4% of those surveyed are Christians.

All respondents have heard of epilepsy and only 18.4% attended a seizure, 61.8% of respondents say they cannot marry or epileptic among those, 83.2% are Christians against 16.8% of atheists; 98.9% of respondents believe that the drugs are effective and among them 49.1% of university intellectuals.

82.5% of respondents claim consult doctor in case of epilepsy without excluding any time the possibility of a pastor or a traditional healer at the same time, for them, 44% are Christians and Muslims 37.3%.

37.9% of respondents believe that epilepsy can continue normal schooling among these, 85% are Christian, and 54% of those surveyed have a university level 46.4% believe that the
customs and traditions influence epilepsy. Among them 82.3% are against Christians 16% Muslims (Tables 1-3).

Table I  Distribution of respondents according to the sociodemographic profile.

| Sex            | Effective | Percentage |
|----------------|-----------|------------|
| Female         | 411       | 45.50%     |
| Male           | 492       | 54.50%     |

| Level of instruction | Effective | Percentage |
|----------------------|-----------|------------|
| Primary              | 47        | 5.30%      |
| Secondary            | 405       | 45.80%     |
| Higher or university | 433       | 48.90%     |

| Occupation            | Effective | Percentage |
|-----------------------|-----------|------------|
| Agriculture           | 43        | 4.80%      |
| Private enterprise    | 144       | 15.90%     |
| Public company        | 106       | 11.70%     |
| Student               | 126       | 13.90%     |
| Public function       | 148       | 16.40%     |
| Household             | 14        | 1.50%      |
| Liberal profession    | 210       | 23.20%     |
| Minier                | 22        | 2.40%      |
| Sale                  | 91        | 10.10%     |

| Residence            | Effective | Percentage |
|----------------------|-----------|------------|
| Annex                | 118       | 12.90%     |
| Kamalondo            | 71        | 7.80%      |
| Kampemba             | 309       | 33.80%     |
| Katuba               | 128       | 14.00%     |
| Kenya                | 68        | 7.40%      |
| Lubumbashi           | 186       | 20.40%     |
| Ruashi               | 33        | 3.60%      |

| Marital Status       | Effective | Percentage |
|----------------------|-----------|------------|
| Single               | 362       | 40.60%     |
| Divorced (e)         | 37        | 4.20%      |
| Married (e)          | 422       | 47.40%     |
| Widow (er)           | 70        | 7.90%      |

Table 2  Distribution of respondents according to the perception of epilepsy and level of study.

| Level of Instruction | Epilepsy | Primary | Secondary | University |
|----------------------|----------|---------|-----------|------------|
| Convulsion (n=91)    | 10.3%    | 7.7%    | 38.5%     | 53.8%      |
| Mental illness (n=148)| 16.7%   | 4.7%    | 54.7%     | 40.5%      |
Curse (n=295) 33.3% 4.7% 48.5% 46.8%
Witchcraft (n=351) 39.7% 5.4% 41.6% 53%

**Ever heard of epilepsy**

| Yes (n=885) 100% | 5.3% | 45.8% | 48.9%
|---|---|---|---|

**Already witness a seizure**

| Yes (n=163) 18.4% | 6.1% | 49.1% | 44.8%
|---|---|---|---|

**Would you marry a (an) epileptic?**

| No (547) 61.8% | 0% | 47.5% | 52.5%
|---|---|---|---|

**Notice of Processing Efficiency**

| Epileptic drug (n=875) 98.9% | 5.4% | 45.5% | 49.1%
|---|---|---|---|
| Do not know (n=2) 0.2% | 0% | 50% | 50%
| No treatment (n=2) 0.2% | 0% | 50% | 50%
| Prayer (n=2) 0.2% | 0% | 100% | 0%
| Nothing (n=2) 0.2% | 0% | 50% | 50%
| Healing treatment (n=2) 0.2% | 0% | 100% | 0%

**If you were epileptic or a member of your family, will you see that?**

| Physician (730) 82.5% | 5.2% | 46.8% | 47.9%
|---|---|---|---|
| Traditional healer (474) 53.6% | 5.5% | 47.5% | 47%
| Pastor (434) 49.0% | 5.3% | 44.9% | 49.8%
| Person (Shame) (187) 21.1% | 10.2% | 42.2% | 47.6%

**Do you think that epilepsy can follow a normal schooling**

| Certainly (n=335) 37.9% | 5.3% | 46.6% | 48.1%
|---|---|---|---|
| Not at all (n=313) 35.4% | 4.5% | 47.3% | 48.2%
| Maybe (n=237) 26.8% | 6.3% | 42.6% | 51.1%

**Do you think that epilepsy can be cured by prayer?**

| Yes (n=623) 70.4% | 6.1% | 44.9% | 49%
|---|---|---|---|

**The influence of prayer you it your judgment to epilepsy**

| Yes (n=471) 53.2% | 5.9% | 45.9% | 48.2%
|---|---|---|---|

**Do you think that prayer may be associated with modern medicine in the treatment of epilepsy?**

| Yes (n=800) 71.2% | 6.5% | 45.6% | 47.9%
|---|---|---|---|

**Do you think that prayer can be associated with traditional medicine in the treatment of epilepsy?**

| Yes (n=251) 28.4% | 6.4% | 49% | 44.6%
|---|---|---|---|

**Do you think that the customs and traditions influence in the occurrence of epilepsy?**

| Yes (n=411) 46.4% | 5.8% | 49.9% | 44.3%
|---|---|---|---|

**Table 3 Distribution of respondents according to perception of epilepsy and religious belief.**

| Religion | Atheist(%) | Christian (%) | Muslim (%) |
|---|---|---|---|
| Epilepsy Convulsion (n=91) 10.3% | 0% | 88.4% | 11.6% |
| Condition               | Yes (%) | No (%) | Total (%) |
|-------------------------|---------|--------|-----------|
| Mental illness (148)    | 16.7%   | 88.3%  | 100%      |
| Curse (295)             | 3.3%    | 96.7%  | 100%      |
| Witchcraft (351)        | 39.7%   | 60.3%  | 100%      |

### Ever heard of epilepsy?

- Yes (885) 1.6% 84.3% 14%

### Already witness a seizure

- Yes (n=163) 18.4% 80.8% 18.6%

### Would you marry a (an) epileptic?

- No (547) 61.8% 83.2% 0%

### Notice of processing efficiency

- Epileptic drug (n=875) 98.9% 1.6% 14.1%
- Do not know (n=2) 0.2% 50% 50%
- No treatment (n=2) 0.2% 50% 0%
- Prayer (n=2) 0.2% 100% 0%
- Nothing (n=2) 0.2% 100% 0%
- Healing treatment (n=2) 0.2% 100% 0%

### If you were epileptic or a member of your family, will you see that?

- Physician (730) 82.5% 69.8% 18.4%
- Traditional healer (474) 53.6% 2.5% 31.1%
- Pastor (434) 49.0% 49.4% 29.7%
- Person (Shame) (187) 21.1% 44.0% 37.3%

### Do you think that epilepsy can follow a normal schooling?

- Certainly (n=335) 37.9% 85.3% 11.8%
- Not at all (n=313) 35.4% 82.9% 15.9%
- Maybe (n=237) 26.8% 85% 14.6%

### Do you think that epilepsy can be cured by prayer?

- Yes (n=623) 70.4% 84.4% 13.8%

### The influence of prayer you it your judgment to epilepsy?

- Yes (n=471) 53.2% 82.8% 15.4%

### Do you think that prayer may be associated with modern medicine in the treatment of epilepsy?

- Yes (n=630) 71.2% 83.9% 14.3%

### Do you think that prayer can be associated with traditional medicine in the treatment of epilepsy?

- Yes (n=251) 28.4% 84.3% 14.6%

### Do you think that the customs and traditions influence in the occurrence of epilepsy?

- Yes (n=411) 46.4% 82.3% 16.3%

### Discussion

Epilepsy in our midst is called "kifwafwa" or "Malari are Ndeke" is a disease subject to strong stigmatization and most sufferers are shunned or even hidden by their families.

In our survey, 39.7% of respondents believe that epilepsy is related to witchcraft and 33.3% to a curse, we must say that our society is dictated by moral considerations and very thorough spiritual, the economic crisis of the past two decades has resulted in our midst a multitude of wake churches, indeed on every avenue in our neighborhoods, you will count a
minimum of 2 churches of revival, spiritual awakening of our people is underpinned by a physical and psychological descent of the shepherds of the churches of the population, resulting in exceptional rise sensational as miracle cures, God provides everything, including jobs and marriages, short Congolese tend to believe in demonizing disease as bad luck, witchcraft and curses, 83.4% of those who answered this question are Christians. The study Mangena conducted in the Limpopo Province in RSA showed that 55.5% of respondents believe that epilepsy is caused by evil spirits [10]; while Tehran Helia’s study gives us a less emotional attitude of people who believe in 62% of cases that epilepsy is a mental illness [11]. In the study of Jiamjit in Thailand, 40% of respondents have estimated that epilepsy is caused by evil spirits, against 17% who say it is the will of Allah [12].

Our respondents have heard of epilepsy, we must say that being an urban entity Lubumbashi, we had the participation of university intellectuals in the order of 48.9% and secondary level 45.8%; lately, the neuroscientists engaged in various companions information on epilepsy with the support of several partners such as the Belgian chemical union (UCB) and Caritas, and more with the advent of the Congolese league against the epilepsy (LUCOCE), the Congolese are aware of ways on mental illness in general, and particularly epilepsy and what to through the media in most of the time. By cons, in the study of Aldrin in New Delhi only 67% of carers inform relatives of patients about the diagnosis of epilepsy in children, while 33% of them are afraid to make the because of the stigma [13], and in the study of Jiamjit North East of Thailand whose main feature is the low level of education, showed that only 60% of respondents have heard of epilepsy mainly by medical personnel [12].

61.8% of our respondents say they cannot marry or epileptic; as we noted above, the level of discrimination is high in our midst, despite the various information campaigns, many people continue to believe that epilepsy can be transmitted through physical contact during ‘a crisis; which explains the abandonment of patients in crisis even by some members of their families in the same vein 58% of respondents in the study Jiamfit Thailand estimates that epilepsy cannot be liked by those around [12]; by Helia against Tehran gives a low percentage of 28% of its respondents who agreed to marry one or epileptic [11]. A Limpopo RSA Mongena shows that 89.7% of respondents believe that physical contact can transmit epilepsy therefore cannot marry or epileptic [10].

82.5% of respondents in our survey say they can see a doctor in case of epilepsy, the feature of this issue is that the respondents have not ruled out the possibility of a pastor, where a traditional healer along the doctor, this is very common in our environment or the modernization of traditional medicine causes more patients to consult with them, especially for chronic conditions such as epilepsy; increasingly many Congolese combine prayer and medical care.

98.9% of respondents believe in the efficacy of medical treatment in our midst, the explanation is simply related to the high level of education in urban areas. As against 60% of respondents in the Limpopo Province in RSA in studying Mangena believe that only God can cure epilepsy [10]; and only 6% of respondents in the study of Aldrin in New Delhi believe in medical treatment [13].

In our study 37.9% of respondents felt that the epileptic children could continue their education, again the fear of parents overcome by the shame of having epilepsy or bewitched children fed stigma at one level or schooling becomes impossible; The reaction of other parents if they learn in the classroom for their children there is an epileptic fears parents thereof prevent the latter to continue studies; this is going in the same direction Aldrin in New Delhi in his study or 45% of caregivers believe that children should stop their schooling in the study 13.90% of respondents in the North of Thailand believe that epilepsy cannot turns like other people [12] and 98% of respondents in the province of Limpopo RSA believe that epilepsy should remain locked up at home [10].

Conclusion

In Africa, epilepsy is not only a disease of the individual, but also society cannot ignore the influence of society on this disease, our study in the city of Lubumbashi Nya no exception. Indeed, 73% of our respondents believe that epilepsy was a religious mystic cause, in a predominantly Christian town, 61.8% believe that the disease is transmitted by physical contact, we also noted a high number of those who would consult a doctor, a traditional healer in epilepsy 82.5%; Unfortunately, this procession of prejudice establishes the rejection of epilepsy in our society with severe consequences to it as non-enrollment, we recommend that the efforts of all for good information on this disease in order to reduce the level of stigma.

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