

# Social and cultural representation of Epilepsy in elderly aged 65 and more, during a community survey in two French Departments (Haute-vienne and Creuse)

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## KEY WORDS

Elderly  
Social and cultural representation  
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## ABSTRACT

Background : Epilepsy is often associated with discrediting representations even in the developed countries. The prevalence of disease is 3-5 in thousand. Purpose : Our purpose was to assess social and cultural representation of epilepsy in the elderly in two French departments (Haute-Vienne and Creuse). Methods: An analysis of the answers given by 380 (190 in Haute-Vienne and 190 in Creuse) persons aged 65 and more, selected with the method of quota, during a face to face interview using a questionnaire which explores the representations of epilepsy. The interview was done in 2003 during the local step of an international multi centric community survey entitled "Mental disorders: Image and Realities in community sample". Results : Beliefs in supernatural causes of epilepsy, witchcraft, curse and punishment are more important in elderly aged 65 and more prevalent compared to the younger subjects; it's the opposite for social causes (conflicts, bereavements, stress). The alimentary interdictions are also persistent. Medical assistance keep a good place in the knowledge of the therapy of epilepsy. It showed that those aged 65 and more in Haute-Vienne had social and cultural representation of epilepsy, generally more pessimistic than those of the persons aged less than 65. Conclusion: The study confirmed a decrease in the stigma about epilepsy. This data suggest a better consideration of the social and cultural representations in the fight against epilepsy even in western countries.

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## Introduction

Epilepsy is a public health problem in developed countries where the disease prevalence is over 3 to 5 per thousand.<sup>1</sup> Currently, beliefs in magical, supernatural causes, contagion or heredity of the disease are a barrier in the global care of People with epilepsy (PWE) especially in SSA.<sup>2,3</sup> The situation is better in western countries but far from ideal. Epilepsy remains stigmatizing and involves family, social and professional disqualifications.<sup>4</sup> The purpose of this paper is to describe the sociocultural representations of epilepsy in a general setting in two French samples.

## Methods

An analysis of the answers given by 380 (190 in Haute-Vienne and 190 in Creuse) individuals aged 65 and more, during a face to face interview using a questionnaire which explores the representations of epilepsy in a sample of 1807 adults (902 in Haute-Vienne and 905 in Creuse) selected with the method of quota has been provided. The interview was done in 2003 during the local step of an international multi centric community survey entitled "Mental disorders: Image and Realities in community sample".

The survey was performed in the town of Limoges and in the geographical area of the psychiatric sectors 87G03 and 87G04 (Haute-Vienne), 23G01 and 23 G02 (Creuse), two departments of the Limousin which is a French region. Sampling was carried out by the method of the quotas, by the Management of the

Research of the Studies on the Evaluation and Statistics (DREES), on the last census; layers according to characteristics: sex, age, socio-professional category, level of education.

The subjects included were questioned using a questionnaire (see table2) on the representations related to the epilepsy prepared by the Institute of tropical neurology and neurological epidemiology of Limoges. The investigators were voluntary students of second or third year in care male nurses: 19 in Haute-Vienne; 21 in Creuse. The duration of investigation was 21 days per site, from November 2002 to January 2003. The data acquisition was carried out by a technician. The analysis of the data was carried out using the software Epi Information 6, SPSS, SAS. All ethical approvals were obtained from respective committees.

## Results

The average age of the respondents participating in the study was  $68 \pm 18,6$  years. Out of the 1807 people which were questioned, the proportion of participants more than 65 years was 21.1% (280 people over 1807). This subclass accounted for almost 1/5 of the total population. This group consisted of 71 men (37.4%) and 119 women (62.6%). The sex-ratio was thus 1.68. Of these about 44.2% lived as couples while 46.3% were widowed, 5.8% were unmarried and 3.7% separated or divorced. Majority of these individuals had completed primary education cycle or secondary schooling (81.1%). About 185 people constituting this group (97.4%) were without occupational activity while 5 (2.6%) had regular employment.

Almost 1/5 of these participants earned a monthly income lower than 840 euro per month and almost 1/3 of these earned 1300 euros or more. The majority of the individuals under this group questioned during this investigation lived either alone (52.7%), or as couples (44.1%). The proportion of people living with three or more members was very low (1.2%).

For the social and cultural Representation of epilepsy, results are summarized in Table 1.

Table 1 : Social and cultural representations of epilepsy in elderly aged 65 and more

Social representation of epilepsy	65 + Mean±SD	< 65 Mean±SD	p
Supernatural	56.5±19.2	48.3±18.2	<0.0001
Alcohol Abuses	50.2±18.7	47.8±18.1	0.0061
Social Causes	47.8±18.7	49.5±18.1	0.05
Heredity	52.4±18.5	45.9±17.8	<0.0001
Care by healers	51.0±19.0	48.2±18.2	0.01
Marriage possible for PWE	56.5±19.2	48.3±18.2	<0.0001
Not schooling child with epilepsy	48.1±18.1	58.1±19.7	<0.0001

Table2 : Questionnaire on the socio-cultural representations of the Epilepsy.

Is the epilepsy different from the psychosis or "madness"? YES/NO
Do you suffer from the disease called "epilepsy"? YES/NO
Did you experience epileptic fits during the two last years? YES/NO
If so, how much events did you have?: 1; 2 to 5; 6 to 10; more than 10
According to you, epilepsy is due to supernatural causes (sorcery, bad fate, bad spirits, curses)? YES/NO
According to you, is epilepsy due to social causes (emotional conflicts, shocks...)? YES/NO
According to you, is epilepsy due to an alcohol abuse? YES/NO
According to you is the epilepsy due to lesions of the brain? YES/NO
According to you, is the epilepsy due to sorcery, a bad fate, the bad spirits or curses? YES/NO
According to you, is the epilepsy is a hereditary disease? YES/NO
According to you, is the epilepsy a contagious disease? YES/NO
According to you, is it possible to cure a suffering patient of epilepsy? YES/NO
According to you, is the epilepsy looked after by drugs? YES/NO
If one of your close relations suffers from epilepsy, advise him you to consult:
A doctor? YES/NO
A healer? YES/NO
According to you, can an epileptics marry? YES/NO
According to you, can a child epileptic go to the school with the other children? YES/NO
Do you currently take a treatment for the epilepsy? YES/NO
If so, which are the drugs which you take against the epilepsy?

Beliefs in supernatural causes of epilepsy, witchcraft, curse and punishment are more important in elderly compared to the younger respondents; The belief that epilepsy is contagious is not wide spread in France.

## Discussion

It is noted that the socio-cultural representations of epilepsy are

more stigmatizing among people over the age of 65 years and more when compared to younger volunteers (Table 1). The concept of "social representation" is complex<sup>5</sup> it is not the reflection of reality but an interpretation of reality. Opinions or knowledge must be distinguished from practices and from anthropological or cultural representations. Studies very often collected opinions or knowledge, which are collective ideas on a disease (for example: it is contagious or magical). Practices represent behavioural response to a disease (for example: feeling of repulsion, rejection or disgust). At last, anthropological representations of the disease refers to a system of cultural, sacred, magical or scientific beliefs.

For some authors,<sup>6</sup> medical issues are really, semantic...". In traditional SSA, while talking about epilepsy, each cultural group focuses on one or many target symptoms. Very often, these are the symptoms of Generalized Tonic Clonic seizure (GTCS).

This representation about the magical origin, contagion, heredity, "biomedical" origin of epilepsy, could influence the type of care given to PWE which has not be explored in this study. A "spiritual" heredity concept as the origin of epilepsy usually appears in the name given to this disease in Africa.<sup>7,8</sup> Many beliefs about epilepsy coexist. The analysis of understanding models of epileptic seizure in different cultural groups, showed the existence of major theories to explain the disease in traditional areas: magical, contagion, "biomedical".<sup>4,9,10</sup> Nowadays, in Africa and in the past, among western countries, epilepsy was widely believed to be contagious, and contact with foam or urine from a patient was thought to transmit the disease. Immediate contacts were always suspicious of contamination. Contact with breath, excretory products, mother's milk, sperm, farts and excretions are still believed to cause seizures in Africa.<sup>11,12</sup> The preparation of a dish in the same crockery or drinking in the same glass are also dreaded.<sup>9</sup>

The social and cultural consequences of these beliefs and ignorance of the disease are extremely prejudicial for the patients. They overall lead to patient marginalization. The exclusion from professional environment is frequent.<sup>13,14</sup> Marginalization also could come from the family. The marital status of PWE is different from that of the general population.<sup>7</sup> Difficulties for PWE to go to school was also underlined.<sup>15</sup> Insufficient knowledge, wrong behaviour and inappropriate belief systems in epilepsy contribute to stigmatization and decrease quality of life of PWE.<sup>16</sup>

## Conclusion

In order to assess social and cultural representation of epilepsy among the elderly in two French Departments (Haute-Vienne and Creuse), we performed a survey in 380 (190 in Haute-Vienne and 190 in Creuse) persons aged 65 and more, during a face to face interview using an established questionnaire. Although, in the developed countries, sociocultural representations of epilepsy have progressed from a magical to a neurophysiological perspective. Some efforts should be made to eliminate the

stigma associated with epilepsy. It is now clear that sociocultural representations should be considered while attempting to improve the global care and quality of life of PWE.

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