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Knowledge and beliefs about epilepsy among people with and without epilepsy in urban Suriname

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ABSTRACT

Reducing the burden of epilepsy in low- and middle-income countries requires understanding of the cultural aspects of epilepsy. This cross-sectional study among individuals attending a clinic in an urban setting in Paramaribo, Suriname aimed to obtain information on the knowledge of and attitudes towards epilepsy and epilepsy treatment, comparing people with epilepsy (PWE) to those without epilepsy. This study also explored the help-seeking behavior and experience of having epilepsy in PWE.

While the results of interviews with 49 PWE and 33 controls compared favorably to studies conducted in similar countries, a significant minority of PWE still rely on traditional remedies. Prejudices regarding social roles, schooling, and occupational choices of PWE also remain prevalent. Currently, the major source of information for both groups is the media, but there could be opportunities for the local epilepsy association to play a larger role.

These findings, despite some selection bias, could be useful in bringing conventional medical treatment strategies to more PWE in Suriname, as well as empower patient organizations in designing stigma-reducing interventions.

1. Introduction

Over sixty million people worldwide suffer from epilepsy, a condition that often also has an important impact for their families and social environment [1,2]. Uncontrolled seizures are known to significantly lower quality of life [3]. In low- and middle-income countries, the majority of people with epilepsy (PWE) remain untreated [4–6].

Efforts towards reducing the burden of epilepsy in low- and middle-income countries require an understanding of the cultural aspects of epilepsy in addition to improvements in health-care infrastructure. If epilepsy is not seen as a treatable disease, people will not seek medical care [7]. Lack of knowledge and a different perception of epilepsy also affect medication compliance [8,9].

Most data on the knowledge of and attitudes towards epilepsy have been collected in sub-Saharan Africa [10] and Asia [11]. Studies on epilepsy and behavior in South America are confined to healthy individuals in Brazil [12–14] or PWE among the rural native community of the Guaraní in Bolivia [15,16]. This study was carried out in Suriname, a small republic in northern South America, with an ethnically mixed population and an average income level classified as upper–middle [17]. The health-care system in Suriname consists of governmental health services, mission hospitals, and private providers [18]. There are a few hospitals with neurology departments [19]. No epilepsy prevalence and incidence data are available. An unpublished door-to-door survey conducted in 1989 in a neighborhood in Paramaribo found a prevalence of 10.5 per 1000 individuals. It is hard to find reliable data from similar surrounding countries, but the epidemiological rates appear to be higher in low- and middle-income countries than in the industrialized northern hemisphere countries [20]. One report indicates that many Surinamers still rely on medicinal plants and traditional knowledge to prevent and cure diseases including epilepsy [21].

This study aimed to obtain information on the knowledge of and attitudes towards epilepsy and epilepsy treatment, comparing people with epilepsy (PWE) to those without epilepsy in Paramaribo, Suriname. We also explore the help-seeking behavior and experience of having epilepsy in PWE.

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2. Methods

2.1. Study population

This cross-sectional study was carried out among individuals attending an outpatient clinic in the university hospital in Paramaribo (study period: October–November 2010). People with epilepsy were selected from patients visiting the epilepsy clinic who personally suffered from epilepsy. Exclusion criteria were significant learning disabilities or language barrier. Individuals without epilepsy served as controls and were selected from people with other health problems visiting the clinic at other days during the same study period. In children under twelve, interviews were held with their caregivers.

2.2. Questionnaires

The questionnaire in both groups comprised items about the knowledge of and attitudes towards epilepsy. Questions regarding treatment strategies and sociodemographic information including age, gender, marital status, religion, ethnicity, level of education, and occupation were also included. A separate list of questions was asked to the group of PWE regarding their epilepsy type, age at onset, seizure frequency, and putative cause of epilepsy.

The questionnaire was designed based on instruments used on studies on epilepsy and behavior in Brazil and countries outside South America with help from native neurology staff members [13,22–29]. Interviews were conducted in Dutch or local *lingua franca* [30].

2.3. Statistical analysis

All data were entered into a database. We expected individuals without epilepsy to do twice as well compared to PWE given the significant stigma found in previous studies in Brazil [12–14]. The minimal total sample size based on inequality of proportions (i.e., 50% vs. 25%) in two independent groups was 64 (alpha: 0.05, power: 0.8, two-tailed chi-square testing).

Proportions and chi-square calculations (P-value < 0.05 was considered significant) for the sociodemographic characteristics and individuals' responses were generated using SAS/STAT® version 9.2 (SAS Institute Inc., Cary, NC, USA).

2.4. Ethics

Ethical approval was obtained prior to data collection from the board of the Academic Hospital Paramaribo, Suriname. All participants provided informed consent.

3. Results

3.1. Sociodemographic characteristics of the respondents

Questionnaires were administered to 49 PWE and 33 individuals without epilepsy. Answers were provided by caregivers in 14 cases. The sociodemographic characteristics of both groups are shown in Table 1. The groups were very comparable with the exception that PWE were statistically more likely to be young, single, or unemployed.

3.2. Clinical characteristics of the PWE

The clinical characteristics of participating PWE are shown in Table 2. The onset of epilepsy was mostly before the age of twenty. Secondarily generalized tonic–clonic seizures were the most frequent seizure type (25%). The majority were on AED treatment (84%). Sixteen were seizure-free (33%). The cause of epilepsy was known for eleven people (22%) and included meningitis, stroke, and neurotrauma.

Table 1
Characteristics of the 82 subjects interviewed.

	PWE (n = 49) n (%)	Controls (n = 33) n (%)	P-value
Gender			
Male	23 (46.9)	15 (45.5)	0.895
Female	26 (53.1)	18 (54.5)	
Age (years)			
<25	14 (28.6)	–	<0.001
25–50	29 (59.2)	16 (48.5)	
>50	6 (12.2)	17 (51.5)	
Ethnicity [a]			
Creole	21 (42.9)	7 (21.2)	0.138
Hindustan	15 (30.6)	18 (54.5)	
Javanese	5 (10.2)	4 (12.1)	
Other	6 (12.2)	4 (12.1)	
Religion [a]			
Christian	28 (57.1)	13 (39.4)	0.089
Hindu	9 (18.4)	15 (45.5)	
Muslim	5 (10.2)	3 (9.1)	
Other	5 (10.2)	2 (6.1)	
Residence [a]			
Paramaribo	28 (57.1)	25 (75.8)	0.132
Elsewhere	19 (38.8)	8 (24.2)	
Family status [a]			
Married	11 (22.4)	20 (60.6)	0.001
Single	25 (51.0)	3 (9.1)	
Cohabiting	9 (18.4)	6 (18.2)	
Divorced	1 (2.0)	1 (3.0)	
Widow	1 (2.0)	3 (9.1)	
School level [a]			
Elementary school	27 (55.1)	11 (33.3)	0.049
High school	9 (18.4)	14 (42.4)	
Continuing education	11 (22.4)	8 (24.2)	
Occupation [a]			
Unemployed	17 (34.7)	1 (3.0)	0.006
Employed	20 (40.8)	20 (60.6)	
Retired	4 (8.2)	6 (18.2)	
Housewife	6 (12.2)	6 (18.2)	

[a] Missing data in two individuals in the PWE group.

3.3. Information sources and knowledge about epilepsy

No significant differences were found in the information sources and knowledge about epilepsy between PWE and controls as shown in Table 3. Two-thirds of controls knew someone with epilepsy, and a similar number had witnessed a seizure.

An important source of information was the media for 39% in the group with epilepsy and 49% in the control group. Despite these sources, only a minority of respondents were capable of naming the correct causes of epilepsy, namely 37% (epilepsy) and 18% (controls). One of the causes mentioned was *fiofio*, a spiritual revenge due to an ancestor's curse. Epilepsy was thought to be a brain disorder in 20% of the PWE group and only 3% of the control group. Thirty-five percent of the PWE knew of the existence of a local epilepsy support group, but only one had ever attended a meeting. Fifty-five percent of PWE, however, expressed interest in attending.

Knowledge about possible symptoms of epileptic seizures is given in Table 4. Among the PWE, 59% could name three or more correct symptoms, which was only moderately higher than in the control group (49%). Symptoms that were often mentioned in both groups were unconsciousness, stiffening and shaking of the body, and foaming at the mouth. A tongue bite was more often mentioned in the group with epilepsy (47% vs. 21%), while falling was more often mentioned in the control group (64% vs. 31%). These differences are not statistically significant.

3.4. Epilepsy treatment beliefs and actions

Ideas on treatment of epilepsy are given in Table 5. People with epilepsy considered epilepsy a curable disorder (57%), but fewer