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Patient Beliefs about Epilepsy and Brain Surgery in a Multi-cultural Urban Population

Nehama Prus and Arthur C. Grant *

Department of Neurology, SUNY Downstate Medical Center, 450 Clarkson Ave. Box 1275, Brooklyn, NY, 11203

Abstract

We assessed beliefs about epilepsy and brain surgery, and the use of alternative epilepsy treatments in a culturally diverse population of people with epilepsy (PWE). Data were obtained from a structured questionnaire administered to 109 PWE treated at a single epilepsy center. Patients were born in 17 countries on five continents. Most patients identified culturally with the Caribbean (41%), USA (39%) or Latin America (9%). 69% of patients endorsed at least one of five stigma-related questions, and 77% used at least one alternative epilepsy treatment. Brain surgery was rated as having a mean dangerousness of 8.3 (1 to 10 scale) among the 94 patients with no history of neurosurgery. In addition, 51% of these patients would *not* consider surgical treatment even if it were guaranteed to stop their seizures without causing deficits. Educational efforts aimed at reducing both epilepsy stigma and fear of resective epilepsy surgery are needed.

Keywords

epilepsy; stigma; epilepsy surgery; complementary medicine

Introduction

Throughout the world epilepsy – the disease once sacred [1] but more often viewed through the lenses of fear and superstition – remains poorly understood by the general public [2–12]. The appearance of a convulsive seizure, the peculiar behaviors that may accompany complex-partial seizures, and the psychic phenomena that often comprise seizure auras have fueled millennia of epilepsy stigmatization. Folk, religious or spiritual notions of its causes and treatments are common, especially in the developing world [2,5,8,10–14]. Such beliefs are often in conflict with those of treating physicians trained in allopathic medicine. There is strong anecdotal evidence that beliefs about brain surgery are often culturally-based, and that resective brain surgery is frequently viewed as a high risk and low benefit procedure.

Very little is known about such beliefs among people with epilepsy (PWE) living in the U.S. [5], and no studies have investigated whether beliefs about epilepsy differ between immigrant groups. Similarly, no studies have probed how PWE view the relative risk and benefit of brain surgery as a treatment option. If patients harbor false or unsubstantiated views of epilepsy

*To whom correspondence should be addressed. Phone 718.270.2959, Fax 718.270.4711, arthur.grant@downstate.edu.

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surgery, then appropriate educational efforts could result in greater acceptance of this underutilized treatment [15].

We sought to assess beliefs about the stigma of epilepsy, causes of epilepsy, and risks of brain surgery, and to determine the use of alternative treatments for epilepsy, in a culturally and ethnically diverse population of PWE.

Methods

Patients 14 years or older attending sub-specialty epilepsy clinics at an academic medical center in Brooklyn, NY, were eligible for the study. Patients seen in these clinics have health insurance (predominantly Medicaid and/or Medicare) and full access to comprehensive epilepsy care. Inclusion criteria included a documented history of epilepsy, and ability to understand and complete the research questionnaire. All eligible patients seen over a five month interval were given the opportunity to participate. Subjects were required to complete the questionnaire without assistance, and a researcher was present to answer questions. Fewer than 20 patients declined due to insufficient time to complete the study. The study was approved by the SUNY Downstate Medical Center institutional review board and subjects were paid for participation.

The anonymous, structured questionnaire had five sections. The first section obtained demographic and clinical data. Several questions addressed cultural background and identity, most importantly, “With what geographic region do you most identify your cultural beliefs, values and morals?”. The second section addressed beliefs about causes of epilepsy, and in one question subjects could endorse any of 18 possible causes that included both allopathic and folk options (e.g. brain tumor and the devil). The third section addressed use of alternative epilepsy treatments, i.e. anything other than what their treating physician recommended. In one question patients were asked which of 15 specific alternative treatments they utilize. The fourth section concerned epilepsy stigma, and the final section concerned beliefs about brain surgery. The non-allopathic possible causes of epilepsy and the alternative epilepsy treatments were chosen after conducting an extensive literature review of folk and culturally determined beliefs about epilepsy around the world. Particular attention was paid to data from Caribbean cultures, given the high proportion of patients from this region seeking care at our center.

Data were analyzed using SPSS (version 16). A one-way analysis of variance (ANOVA) was used for all statistical comparisons. Factors included cultural identity, household income, and educational level. Cultural identity was simplified to four levels: Caribbean, USA, Latin America, and other. Education was simplified to three levels (≤ 11 years, High School graduate, \geq some college), and income was simplified to four levels ($\leq 10,000$, 11 – 20,000, 21 – 50,000, $> 50,000$). A single dependent variable reflecting use of alternative epilepsy treatments was created by adding, for each patient, the number of alternative treatments used. The same process was used to create a single variable reflecting perception of epilepsy stigma, by adding the number of stigma-related questions endorsed affirmatively (see Table 2). Significance level was set at 0.05 for each test without any correction for multiple comparisons, given the exploratory nature of the analysis.

Results

Demographic data for the 109 respondents are shown in Table 1. Patient age ranged from 14 to 72 years. Patients were born in 17 countries on five continents, while their parents were born in 20 countries. The number of patients and parents born in each country is shown in Supplementary Table 1. Of 66 patients born in the U.S., 28 (42%) identified culturally with another world region (Caribbean – 15, Latin America – 8, Africa – 3, Europe – 1, Pacific Islands – 1). Of the 96 patients at least 19 years old, 82 (85%) had completed high school, and only

27 (28%) were employed. Over half of all patients (57%) had an annual household income less than \$10,000, and most of these patients reported no income other than public assistance.

The mean (S.D.) number of seizures in the previous 4 weeks was 2.3 (1.0) and the median was 1. Only 42 (39%) patients reported having no seizures in the prior four weeks. The mean (S.D.) duration of epilepsy was 18.4y (13.3), and the mean (S.D.) fraction of life with epilepsy was 52% (32). Patients were taking a mean (S.D.) of 1.8 (0.9) anti-epileptic drugs.

Epilepsy Stigma

Seventy-five (69%) subjects endorsed at least one of five stigma-related questions (Table 2). About one-third of patients felt that there is “a stigma, shame or disgrace associated with having epilepsy”, and a similar fraction of patients endorsed the other four questions in the stigma-related direction. Twenty-six (24%) patients would not allow their child to marry someone with epilepsy.

Causes of Epilepsy

Patients endorsed established causes of epilepsy at relatively high rates compared to folk, spiritual or religious causes (Table 3). Interestingly, drug or alcohol abuse was endorsed just as often (n = 30, 28%) as stroke and mental or psychological disorder as a cause of epilepsy.

Alternative Epilepsy Treatments

Eighty-four (77%) patients reported currently using at least one alternative epilepsy treatment (Table 4). Prayer was by far the most common alternative treatment, utilized by 54% of patients, followed by meditation (24%) and vitamins (17%).

Risk of brain surgery

On a 1 to 10 scale, brain surgery was rated as having a mean dangerousness of 8.3 among the 94 patients with no history of brain surgery. Death and memory loss were both endorsed by 60 (55%) patients as “frequent negative outcomes” of brain surgery (Table 5). Considerable skepticism about the efficacy and safety of epilepsy surgery was evident in how patients responded to two related questions about their willingness to undergo surgical treatment (Table 5). Among the 94 patients with no history of brain surgery, only 46 (49%) would consider surgery if their doctor told them it were guaranteed to stop their seizures without causing deficits.

Statistical Analyses

The number of stigma questions endorsed affirmatively, number of alternative epilepsy treatments used, and perceived risk of brain surgery each did not differ significantly on the basis of cultural identity, income level, or education.

Discussion

Most adults with epilepsy can lead seizure-free lives with appropriate anti-epileptic drug (AED) treatment [16], and for those not rendered seizure free with medication, epilepsy surgery is often a safe and highly effective alternative [17,18]. Unfortunately, epilepsy surgery for medically uncontrolled temporal lobe epilepsy is “arguably the most underused of all effective therapeutic interventions” [15].

The results of this study help elucidate the basis for this treatment gap. While prior reports have emphasized disease or physician related factors, such as the difficulty in reliably identifying medical intractability early in the disease course or delay in referral of patients to

comprehensive epilepsy centers [15], our data indicate that patient beliefs can be an important additional obstacle to obtaining epilepsy surgery. These data reveal both an alarming fear of brain surgery in general, and a remarkable misconception of surgical risks, with 55% of patients with no history of brain surgery considering both death and memory loss *frequent* neurosurgical outcomes. Only 51% of patients with no history of neurosurgery would consider epilepsy surgery even when their physician told them it was guaranteed to stop their seizures without causing any brain damage. These data reveal a previously underappreciated but also remediable barrier to PWE obtaining an effective, safe and potentially curative treatment.

Two other potential targets for educational efforts aimed at PWE emerge from this study. First, in this population of PWE, as in many others [4,6,8,9,19], there is a high prevalence of perceived epilepsy stigma. Over two-thirds of the patients endorsed at least one stigma-related question. In addition to its effect on sense of well-being and stress, increased perceived stigma is associated with lower levels of medication management, medication adherence, and patient satisfaction [20]. Second, again consistent with prior studies [21–24], a large majority of PWE in this study used complementary epilepsy therapies. While several of these alternative treatments may improve sense of well-being and reduce stress (e.g. prayer, meditation, exercise), none has a proven benefit specific to epilepsy, and at least one – herbal preparations – is potentially harmful.

Thus, this study illuminates two broad topics for an educational intervention aimed at PWE: epilepsy stigma and epilepsy treatment. Within the latter, the risks and benefits of epilepsy surgery and alternative treatments are areas deserving special attention. Providing patients with accurate information about these subjects could significantly impact quality of care and clinical outcomes. In particular, it could increase acceptance of epilepsy surgery as an efficacious and safe treatment option; increase sense of well-being and medication adherence by lowering perceived stigma; and reduce out of pocket expenses on ineffective and potentially harmful treatments. The latter point is especially relevant for an economically disadvantaged population such as the one surveyed in this study.

A limitation of this study is that the results may not generalize to PWE whose economic and clinical circumstances differ from those of the study population. Most study participants were economically disadvantaged and had a relatively high rate of pharmacoresistant epilepsy. The latter quality is typical of patients seen in sub-specialty epilepsy clinics, but not of patients seen in general neurology practice. Patients with greater economic security and higher educational attainment may feel less stigmatized, though the available data suggest that epilepsy stigma is a world-wide phenomenon [2–4,6–9,¹¹,¹²,14,19,20,25]. With respect to the use of alternative epilepsy treatments, the overall rate of 77% in our population is higher than that reported in other U.S. populations of PWE, where the rate is typically about 40% [22–24]. This discrepancy may be due to the fact that many of our patients consider themselves devoutly religious and thus may turn to prayer at a relatively high rate, or that the lack of seizure control with medications motivates the search for unconventional treatments. The alternative treatments in greatest use by our patients are consistent with findings from other U.S.-based studies [22, 24]. Although the economic and educational status of our subjects may have influenced the results, these factors were statistically non-significant predictors of patient beliefs. Thus, we suggest that these data may in fact generalize to other populations of PWE.

Contrary to our expectations, cultural identity did not significantly affect stigma, perceived risk of brain surgery, or use of alternative treatments. There are at least two possible explanations for this finding. First, 94% of the subjects identified with a Western culture, and 89% with the Caribbean, U.S. or Latin America. The Western allopathic model of health and disease is dominant in all of these regions, with only rare exceptions. For instance, in Haiti the most common religion is voodoo, and there are abundant case reports of Haitian PWE

attributing their seizures to spirit possession [5]. Indeed, both of our Haitian patients endorsed abandonment by good spirits, and one also endorsed lack of faith, as causes of epilepsy. Second, while 57% of patients identified culturally with another world region, all of them live in the U.S. and have been influenced, to one degree or another, by the view of health and disease dominant in this culture.

This anonymous, questionnaire based study confirms and extends findings from prior surveys of patient beliefs about epilepsy and its treatment. In particular, we demonstrate a previously unrecognized and clinically unjustified fear of brain surgery, and skepticism of its utility in epilepsy. These data reinforce the need for educational intervention programs in PWE, perhaps particularly in patients who lack the cognitive, social or financial resources to independently seek out such information. Based on these data, we hope to design and test a comprehensive behavioral intervention at our center, with the goals of increasing medication adherence and quality of life in PWE.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Patient demographics and cultural identity.

	Patients (%)
Number	109
Age, y, mean \pm SD	36.8 \pm 15.2
Female	65 (60)
Cultural Identity	
Caribbean	45 (41)
USA	43 (39)
Latin America	10 (9.2)
Europe	4 (3.7)
Africa	3 (2.8)
Other	4 (3.7)
Religion, n = 108	
Christian	92 (85)
None	11 (10)
Jewish	3 (2.8)
Buddhist	2 (1.9)
Birthplace	
USA	66 (61)
Caribbean	26 (24)
South America ^a	7 (6.4)
Other	10 (9.2)
Education, n = 108	
<8 years ^b	8 (7)
8–11 years ^c	12 (11)
HS graduate	47 (44)
Some college	26 (24)
College degree	15 (14)
Employed, n = 96 ^d	27 (28)
Household Income, n = 105	
\$0-\$10,000 ^e	60 (57)
\$11,000-\$20,000	11 (11)
\$21,000-\$50,000	22 (21)
>\$50,000	12 (11)

^aThese 7 patients were born in Guyana which identifies culturally with the Caribbean nations.

^bTwo of these subjects were 14 years old. The remaining 6 were \geq 34 y.

^cFive of these subjects were between 14 and 17 years old. The remaining 7 were \geq 27 y.

^dpatients 19 years or older

^eMost of these patients reported no income other than public assistance.

Table 2

Stigma of Epilepsy.

	Patients (%)
Is there a stigma/shame/disgrace associated with having epilepsy?	32 (29)
Do you hide your epilepsy from friends/coworkers/relatives?	22 (20)
Do you think people are scared of you because you have epilepsy?	25 (23)
Do you think epilepsy lowers your intelligence?	38 (35)
Would you allow your child to marry someone who has epilepsy?	82 (76)

Table 3

Causes of Epilepsy.

	patients (%)
Tumor	60 (55)
Brain Disorder	49 (45)
Genes/Genetics	38 (35)
Drug/alcohol abuse	30 (28)
Stroke	30 (28)
Mental/psychological disorder	30 (28)
Brain aneurysm	29 (27)
Meningitis	14 (13)
Sexually transmitted infections	4 (3.7)
The devil	3 (2.8)
Abandonment by good spirits	2 (1.8)
Curse	2 (1.8)
Sins committed in past life	2 (1.8)
Spirits of the dead	2 (1.8)
Lack of spiritual faith	1 (0.9)
Evil Spirits	0
Witchcraft	0
Sins committed in this life	0

Table 4

Alternative Epilepsy Treatments.

	Patients (%)
Prayer	59 (54)
Meditation	26 (24)
Vitamins	19 (17)
Diet	12 (11)
Exercise	4 (3.7)
Herbal preparation	4 (3.7)
Acupuncture	3 (2.8)
Religious ceremony	3 (2.8)
Spiritual healing	2 (1.8)
Other	4 (3.7)

Table 5

Perception of brain surgery.

<i>“Frequent negative outcomes” of brain surgery</i>	
	Patients (%)
Death	60 (55)
Memory loss	60 (55)
Paralysis	39 (36)
Stroke	28 (26)
Personality change	26 (24)
<i>Willing to have epilepsy surgery if seizure freedom were guaranteed^a:</i>	
No prior brain surgery (n = 94)	46 (49%)
No prior brain surgery and ≥ 1 seizure in the past 4 weeks (n = 53)	27 (51%)

^a“If your epilepsy doctor told you that brain surgery was guaranteed to stop your seizures without causing brain damage, would you be willing to have surgery?”