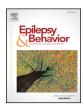
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# Control perceptions in epilepsy: A transcultural case–control study with focus on auras



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#### ABSTRACT

Objective: General Locus of Control (GLoC) is used to measure the extent to which people perceive life events as results of their own actions or external factors. This study analyzes the relationship between GLoC and people with epilepsy's (PWE) clinical characteristics, levels of anxiety, depression, religiosity/spirituality, and quality of life, with particular attention to possible influences of auras.

Methods: A case–control study was carried out with 186 consecutive patients with a definite diagnosis of epilepsy in Brazil and Lithuania. Besides clinical and demographic data, all patients answered to internationally validated scales: Rotter's GLoC, Hospital Anxiety and Depression Scale (HADS), Quality of Life in Epilepsy (QOLIE-31), and Index of Core Spiritual Experiences-Revised (INSPIRIT-R).

Results: Patient's mean age was  $36.15 \pm 13.75$  years, 61.3% were female, mean age at onset of epilepsy was  $17.27 \pm 13.59$  years, and monthly seizure frequency was  $8.22 \pm 20.00$ . People with epilepsy were more depressed than controls, (p=0.03). Within the group with epilepsy, patients reporting auras and reacting to them had higher levels of depression (p=0.002) and anxiety (p=0.004) and lower QOLIE-31 (p=0.01) score but did not differ in GLOC (p=0.73) or INSPIRIT-R (p=0.71). Patients with perceived ability to prevent seizures in response to auras had no increased levels of depression and anxiety.

Conclusions: General Locus of Control externalization in PWE was not confirmed. To perceive and be able to react to auras is associated with increased anxiety and depressive symptoms in PWE but not if it results in preventing seizures. No transcultural differences in these parameters were found.

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#### 1. Introduction

One of the most problematic features of epilepsy is the loss of control during seizures, which together with their unpredictability, may be one of the reasons why people with epilepsy (PWE) have higher rates of depression, anxiety, and suicidality, and lower quality of life [1–7].

Locus of Control (LoC) is a concept introduced in 1966 by Rotter [8]. It is used to determine the subjective perception of control over one's own lives. Locus of Control may be classified as "internal" when persons feel that their life is the result of their own behavior, abilities, and choices or "external" when they ascribe significant life aspects to

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external determinants such as chance, higher powers, or influential other people. In the field of health, general LoC (GLoC) has been supplemented by Health Locus of Control (HLoC) which likewise can be "internal" (own control of disease and its management) or "external", the latter divided into chance (fate, luck, superior powers) and significant others (health personnel, relatives, friends) [9,10].

Previous studies reported that epilepsy – like some other chronic diseases – is often correlated with external LoC, both general and health-related [11–18]. One of the reasons could be the repetitive experience of loss of control by seizures [16].

The term aura describes subjective symptoms at the onset of seizures with later loss of awareness whereas isolated auras are focal sensory seizures [19]. Auras are reported in 55–65% of focal epilepsies. However, for reasons still unexplained, patients with generalized epilepsies also may report auras, even as frequently as in focal epilepsies

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[20]. Auras may, by their constant repetition, make PWE more aware of their condition and its inherent risks but also allow them to alert their entourage, take measures to prevent injuries, or even prevent a fully developed seizure thus, decreasing the risks [21]. Preservation of self-control challenged by seizures is important for patients' LoC and emotional well-being [2,3].

Devillis et al. investigated 289 PWE in relation to learned helplessness [12]. Compared with a normative sample, PWE showed significantly reduced internal GLoC and increased chance HLoC together with increased depression scores. Both auras and perceived ability to avoid seizures were correlated significantly with increased internal GLoC and HLoC and decreased depression scores. Likewise, patients who avoid seizure precipitants and attempt to inhibit seizures qualified as "high controllers" in a semistructured interview [17]. In the only other study addressing the relation of auras to LoC, Lohse et al. found stronger internal HLoC in patients who reported an ability to react to an aura [13]. This study did not address GLoC, beyond health. The present investigation compares GLoC, quality of life, and anxiety and depression scores of patients with no auras and auras with and without the possibility to react. Some earlier studies found an increased "chance" HLoC in PWE, which includes superior powers and God [12]. Our transcultural approach allowed us to compare control perceptions in a society with strong traditional religious beliefs and another, much more secularized society, the hypothesis being that higher religiosity would be related to more external LoC.

#### 2. Material and methods

#### 2.1. Subjects

This was a case-control, transcultural study carried out in two centers for comprehensive care of epilepsy: (1) Epilepsy Surgery Center of Santa Catarina — University Hospital of Federal University of Santa Catarina in Florianopolis, Brazil (with a catchment area of 6 million people) and (2) Epilepsy Center – Vilnius University Hospital Santaros Klinikos in Vilnius, Lithuania (with a catchment area of 2 million people). All individuals with a definite diagnosis of epilepsy according to the International League Against Epilepsy (ILAE) guidelines [1,22] (supported by a detailed clinical history, neurological examination, electroencephalography, and a 1.5-T brain magnetic resonance imaging) and treated with standard antiepileptic drugs (AEDs) were recruited consecutively from August 2015 to March 2017. As controls, healthy volunteers, matched according to age, sex, and education were recruited randomly from the general population of the respective towns in the same period. Exclusion criteria were the following: patients under 18 years old, illiteracy or impossibility to respond to the questionnaires due to cognitive and/or psychiatric comorbidities, seizure-free PWE or in remission due to previous epilepsy surgery, and subjects with nonepileptic seizures.

#### 2.2. Procedures

Clinical and demographic data were obtained through a semistructured face-to-face interview. Questionnaires commonly used in PWE, therefore allowing comparison between different patient populations, were applied:

- Quality of life in epilepsy (QOLIE-31) [23,24]: this is the globally most used questionnaire for surveying health-related quality of life in epilepsy. The scale is scored from 0 to 100, higher scores reflecting better quality of life;
- Hospital Anxiety and Depression Scale (HADS) [25,26]: this simple, quick, and easy to use questionnaire, useful for screening and to track progression of anxiety (HADS for Anxiety (HADA)) and depression (HADS for Depression (HADD)), which commonly coexist, has been validated in many languages, countries, and settings

- including general practice and community settings. Scores for each subscale (anxiety and depression) range from 0 to 21 with scores higher than 8 categorized as positive for anxiety or depression;
- Index of Core Spiritual Experiences-Revised (INSPIRIT-R) [27,28]: an
  instrument used to assess religious and spiritual experiences,
  developed by Kass et al. originally in English and with a Portuguese
  version. This questionnaire comprises seven questions, and its score
  ranges from 1 to 4, with higher scores meaning higher religiosity/
  spirituality (HRS).

All patients were stepwise dichotomized 1) according to the presence or absence of auras (AURA yes or no); 2) according to their self-reported ability to perceive and react to auras (yes or no; *i.e.*, being able to prepare the entourage, taking measures to prevent further injuries — REACT group); and 3) concerning their self-reported ability to avoid subsequent seizures after the perception of an aura (yes or no — AVOID group). Those reporting auras were asked to identify one or more types of auras from a list including 13 of the most frequent auras according to the ILAE's Glossary of Descriptive Terminology for Ictal Semiology [19].

#### 2.3. Rotter's GLoC instrument

The GLoC instrument consists of 29 multiple-choice questions asking the individual to choose between two opposing views or opinions on a given topic or category they most agree with [8]. These alternative statements are formulated to enclose either an internal or external LoC point of view [i.e., a — "Becoming a success is a matter of hard work, luck has little or nothing to do with it" (Internal) versus b — "Getting a job depends mainly on being in the right place at the right time" (External)]. The final score is defined as the sum of all answers indicative of an external LoC on a scale of 0 (maximum internal LoC) to 23 (maximum external LoC). Six neutral questions serve as distractors, preventing participants from realizing the nature and objectives of the test to minimize a possible societal expectation bias. This instrument was recently validated in Brazil [29].

#### 2.4. Statistics

Statistical analysis was performed using GNU PSPP4 software package for Mac OSX. The descriptive analysis was performed to characterize the sample. Power calculations were performed on the basis of the standard deviation (SD) found in an earlier study for our primary outcome, internal LoC [13]. Quantitative variables were expressed as mean  $\pm$  SD while qualitative variables were expressed as percentages. Intra/intergroup and univariate analyses were performed to establish the degree of association between the dependent variable (GLoC score) and independent variables (presence or absence of auras and their characteristics, clinical–demographic variables, QOLIE-31, HADS, and INSPIRIT-R) through standardized statistical tests, accordingly: Chi-square test, Fisher's exact test, Student's t-test, and Pearson's correlation. A value of p < 0.05 was considered statistically significant.

#### 2.5. Ethics

All procedures were carried out in accordance with the Declaration of Helsinki, 2014, and the Uniform Requirements for manuscripts submitted to Biomedical Journals. The study was only started after approval by the Ethics Committees for Human Research of the two involved universities. All subjects signed an informed consent form and voluntarily agreed to participate in this study.

#### 3. Results

A total of 186 PWE were enrolled, 111 from Lithuania and 75 from Brazil; 114 were women (61.3%), and mean age was  $36.15 \pm$ 

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