Physical activity, stigma, and quality of life in patients with epilepsy

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ABSTRACT

Indication of physical activity (PA) for people with epilepsy (PWE) is debatable. This study investigated whether the International Physical Activity Questionnaire (IPAQ) score is related to the clinical aspects of epilepsy, QOLIE-31, and the Stigma Scale of Epilepsy (SSE) score of 67 PWE at a significance level of 5% (p < 0.05).

About one-third (32.8%) of the PWE were sedentary/irregularly active. Lower QOLIE-31 scores and higher SSE scores were found in PWE who did not practice PA for fear of seizures and in sedentary/irregularly active PWE. Twenty-three percent of the PWE stopped practicing PA for fear of seizures. The predictive factors in the logistic regression equation for not practicing physical activity for fear of seizures were the presence of depressive disorder (p = 0.049) and temporal lobe epilepsy with hippocampal sclerosis (TLE-HS) (p = 0.024).

Most PWE are sedentary and do not practice PA for fear of seizures. Physical activity is negatively influenced by clinical aspects of epilepsy. Less PA is associated with depressive disorder, worse quality of life, and higher perception of stigma.

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1. Introduction

Adult people with epilepsy (PWE) have more sedentary lifestyles and practice less physical activity (PA) than the general population [1–4]. However, the reasons for PWE and the general population having different health behaviors have not been clarified. A possible explanation is that many PWE incorrectly believe that PA can induce seizures and/or increase their frequency. Some may fear prejudice and/or perceive social and cultural stigma [5,6].

Some studies have investigated whether PA is related to the clinical aspects of epilepsy and quality of life in PWE [1,6–10]. However, studies that assess the relationship between PA and perception of stigma have not been found.

This study hypothesizes that prejudice and stigma are stronger determinants of PWE’s level of PA than the clinical aspects of epilepsy. Therefore, the objective of this study was to measure the level of PA in PWE and assess whether the said level is related to the perception of stigma, QoL, clinical aspects of epilepsy, and sociodemographic characteristics of PWE.

2. Methods

2.1. Patients

Consecutive PWE aged more than 20 years were recruited at the epilepsy outpatient clinic of the Hospital and Maternity Hospital Celso Pierro (PUC–Campinas), Brazil. Epilepsy was diagnosed according to the International Classification of Epilepsies and Epileptic Syndromes [11] criteria from the International League Against Epilepsy (ILAE).

The psychiatric service of the hospital investigated whether the patients had psychiatric comorbidities according to the DSM-IV and ICD-10 criteria. The PWE were then divided into two groups, one with and one without depressive disorder.

A questionnaire collected sociodemographic (age, gender, and education level) and clinical data (age at seizure onset, seizure type and frequency, duration of epilepsy, number of antiepileptic drugs (AED) taken, and epileptic syndrome).

Patients who had difficulty understanding the questions in the instruments because of low education level or mental disability were excluded, as well as those with other disabling chronic diseases.

The participants were informed about the study protocol, and they signed a consent form before joining the study. The study was approved by the Human Research Ethics Committee of PUC-Campinas.

2.2. Procedure

The PWE answered the following questionnaires:

- Specific questionnaire about the relationship between PA and seizures, with the following yes–no questions: 1. Do you believe PA can trigger seizures? 2. How about in your case, can PA trigger seizures? 3. Do you avoid PA because of seizures?
- International Physical Activity Questionnaire (IPAQ) — Short Form [12]: this instrument measures the level of PA in the last week in different contexts (work, commuting, home chores, leisure-time activities, and transportation).

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activities, and sedentary activities). The IPAQ has four questions that measure PA duration and frequency. The level of PA is classified as sedentary, irregularly active, active, or very active. The IPAQ has been adapted and validated for Brazil [13].

- **Stigma Scale of Epilepsy (SSE) [14]:** this multiple-choice questionnaire quantifies the degree of stigma perceived by adults in different contexts (attitudes and behavior towards PWE, perception and feelings regarding seizures, social aspects associated with having epilepsy). The scale has 24 items distributed in five domains, and each item has four answer options scored from 1 to 4 (1 = not at all; 2 = a little; 3 = a lot; 4 = totally). The results are transformed into 0 to 100 points. Perception of stigma increases with score.

- **Quality of Life in Epilepsy Inventory (QOLIE-31) [15]:** this is an epilepsy-specific QoL inventory validated in Brazil [16]. This inventory scores seven domains individually and combines them into a total score. The overall score ranges from 1 to 100. Higher scores indicate higher QoL.

### 2.3. Data analysis

The study determined whether the IPAQ scores were related to the scores in the specific questionnaire about the relationship between PA and seizures, SSE, and QOLIE-31, to the clinical aspects of epilepsy, and to the PWE's sociodemographic characteristics.

The PWE were classified into two groups, sedentary/irregularly active or active/very active, according to their IPAQ scores. Epilepsy was considered to be under control in individuals who had not had seizures in the last 12 months.

The continuous variables were analyzed descriptively (mean, standard deviation, frequency, and percentage (%)). The categorical variables were tabulated according to their absolute frequency (n) and percentage (%). The independent t-test (for categorical data) determined whether the mean scores between the groups differed significantly between individuals, and Pearson's correlation coefficients (for continuous data) verified whether the variables were linearly associated.

Based on the significant correlations, logistic regression determined whether the predictor variables were related to the binary or continuous outcome variables (dependent variables) with p < 0.10 in the respective prior correlation analyses (independent variables). The data were treated by the software IBM SPSS Statistics, version 22. The significance level was set at 5%.

### 3. Results

#### 3.1. PA: clinical and sociodemographic aspects

Sixty-seven (55.2% females) PWE aged 20 to 50 years participated in the study. Twenty-two (32.8%) PWE were diagnosed with probably symptomatic focal epilepsies, and 45 (67.1%) PWE were diagnosed with symptomatic focal epilepsies. Twenty-eight PWE were diagnosed with temporal lobe epilepsy with hippocampal sclerosis (TLE-HS). They were surgery naïve. Table 1 shows the PWE’s clinical aspects.

The mean SSE score was 46.8 (+ 16), and the overall QOLIE-31 score was 58.5 (+ 16.7).

According to the IPAQ, 22 (32.8%) PWE were sedentary/irregularly active, and 45 (67.1%) were active/very active.

The IPAQ-based level of PA (active/very active vs. sedentary/irregularly active) did not differ by the clinical aspects of epilepsy or PWE's sociodemographic characteristics (Table 2).

One-third (33.3%) of the PWE believe that PA can trigger seizures, and 22.9% stopped practicing PA for fear of seizures.

Uncontrolled seizures (chi-square test; p = 0.047) and depressive disorder (chi-square test; p = 0.004) were significantly more prevalent in PWE who believed that PA can trigger seizures.

#### 3.2. PA: SSE and QOLIE-31

Sedentary/irregularly active PWE had significantly higher SSE scores and lower overall QOLIE-31 scores than active/very active PWE (Table 2).

The PWE who stopped practicing PA for fear of seizures had significantly higher SSE scores and lower QOLIE-31 scores (Table 3).

Logistic regression assessed the study factors' potential to stop PWE from practicing PA for fear of seizures (the reference being not practicing PA). The following variables were included: disease duration, seizure frequency (uncontrolled × controlled), depressive disorder (present × absent), epileptic syndrome (TLE-HS × other epileptic syndromes), QOLIE-31 (total score), and SSE. The following factors were statistically significant: SSE score (p = 0.01), presence of depressive disorder (p = 0.049), and TLE-HS (p = 0.024). Other clinical aspects of epilepsy and the QOLIE-31 score were excluded from the equation because they were not significant (Table 4).

### 4. Discussion

This study assessed whether PA is related to the perception of stigma, QoL, and the clinical aspects of epilepsy in 67 PWE with mean disease duration of 24 years. Less physical activity is associated with higher perception of stigma, low QoL, and clinical aspects of epilepsy.

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**Table 1**

| Sociodemographic and clinical aspects of 67 people with epilepsy (PWE). |
|------------------|------------------|------------------|
|                  | N (SD or %)      |                  |
| Age (y)          | 44.2 (± 12.2)    |                  |
| Females          | 37 (55.2%)       |                  |
| Education level (y) | 6.3 (± 4) |                  |
| Age at first seizure (y) | 19.8 (± 15) |                  |
| Epilepsy duration (y) | 24.2 (± 14.3) |                  |
| Seizure type — focal | 56 (83.5%) |                  |
| Seizure frequency — uncontrolled | 26 (38.8%) |                  |
| Antiepileptic drugs — one | 31 (46.2%) |                  |
| Depressive disorder — present | 21 (31.3%) |                  |
| TLE-HS/other epileptic syndromes | 28 (41.7%), 39 (58.2%) |                  |

TLE-HS: temporal lobe epilepsy with hippocampal sclerosis.

**Table 2**

<table>
<thead>
<tr>
<th>IPQ</th>
<th>Sedentary/irregularly active (n = 22)</th>
<th>Active/very active (n = 45)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (y)</td>
<td>45.4 (± 12.9)</td>
<td>41.9 (± 10.4)</td>
<td>0.238</td>
</tr>
<tr>
<td>Education level (y)</td>
<td>6.0 (± 3.7)</td>
<td>6.8 (± 4.5)</td>
<td>0.456</td>
</tr>
<tr>
<td>Age at first seizure (y)</td>
<td>19.5 (± 15.1)</td>
<td>203.0 (± 15.4)</td>
<td>0.849</td>
</tr>
<tr>
<td>Epilepsy duration (y)</td>
<td>25.8 (± 14.3)</td>
<td>21.5 (± 12.3)</td>
<td>0.214</td>
</tr>
<tr>
<td>SSE</td>
<td>53.5 (± 15.5)</td>
<td>43.1 (± 14.5)</td>
<td>0.03*</td>
</tr>
<tr>
<td>QOLIE-31 (overall score)</td>
<td>50.2 (± 17.6)</td>
<td>59.8 (± 13.7)</td>
<td>0.01*</td>
</tr>
</tbody>
</table>

IPAQ: International Physical Activity Questionnaire; SSE: Stigma Scale of Epilepsy; t-test. * p < 0.05.

**Table 3**

<table>
<thead>
<tr>
<th>SSE and QOLIE-31 scores of 67 people with epilepsy (PWE) according to their score in the questionnaire about the relationship between PA and seizure.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you stopped practicing PA for fear of seizures?</td>
</tr>
<tr>
<td>-------------------------------------------------------</td>
</tr>
<tr>
<td>No (77%)</td>
</tr>
<tr>
<td>Yes (22.9%)</td>
</tr>
<tr>
<td>p-Value</td>
</tr>
</tbody>
</table>

SSE: Stigma Scale of Epilepsy; t-test. * p < 0.05.
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