



Who are the individuals diagnosed with epilepsy using the Public Health System in the city of Pelotas, southern Brazil?



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ABSTRACT

The aim of this study was to describe sociodemographic, clinical, behavioral, nutritional, and health-related variables from people with epilepsy. A descriptive observational study was carried out in the city of Pelotas, southern Brazil. Sociodemographic, clinical, behavioral, nutritional, and health-related variables were collected. A univariate analysis was performed, calculating the measures of central tendency for continuous variables and proportions for categorical ones. The sample consisted of 101 people, age ranging from 12 to 75 years, mostly male (50.5%) and white (59.4%). Only 37.2% from the sample was employed, and the average income was R\$ 788.00 Brazilian Reais (US\$ 245.90 at the moment of the interview). From all the subjects, 65.6% was in treatment with monotherapy, 62.9% presented more than 15 seizures during the life, 67.3% showed active epilepsy, 64.6% were physically inactive, 52.5% presented normal body mass index, and 50% showed generalized seizures. The most used antiepileptic drug was the carbamazepine. The average score of depression was 12.6 ± 4.1 points and 34.6% showed severe depressive symptoms (equal or higher than 15 points). The mean score of trait and state anxiety was 12.2 ± 3.6 and 15.1 ± 3.4 points, respectively (ranging from 6 to 24 points). The mean score of quality of life and stress was 63.2 ± 18.2 (ranging from 0 to 100 points) and 21.2 ± 7.1 points (ranging from 0 to 40 points), respectively. Considering the medication side effects, the mean score was 42.4 ± 8.9 points, 38.5% showing high rates (higher than 45 points), and only 16% showing good sleep quality. In conclusion, these results are important to improve understanding of these individuals' disease and to subsidize the specific public policies in countries of low and middle income.

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1. Introduction

Epilepsy is one of the most prevalent neurological diseases affecting approximately 65 million people around the world [1]. The estimates for this disease in the world vary considerably, however, the general prevalence is 700 cases per 100,000 inhabitants and its incidence is 48 cases per 100,000 people in developed countries [2]. Considering low and middle income countries, the prevalence and incidence rates are 1000 and 70 per 100,000 inhabitants, respectively [3,4].

Epilepsy is characterized by a brain disorder generating a persistent risk to epileptic seizures as well as neurobiological, cognitive, and social alterations [5]. The seizures are characterized by signals and transitory symptoms due to abnormal and excessive neuronal activity in the brain. The following are characteristics of an epileptic seizure: conscious

alterations, motor, sensitive, or sensory events in addition to autonomous or involuntary psychic events [6].

It is a chronic condition directly affecting one's psychological, social, and labor factors [7]. People with epilepsy are more sensitive to some psychiatric comorbidities, the most common are anxiety and depression which negatively affect the individuals' quality of life [8–10].

A study carried out by Kobau et al. [11] using nationwide data from 2010 National Health Interview Survey (United States of America) compared and estimated the prevalence of reporting good or better physical and mental health among adults with five selected chronic conditions including epilepsy, diabetes, heart disease, cancer, and hypertension. The percentages of adults with epilepsy who reported good or better physical health (52%) or mental health (54%) were significantly below the Healthy People 2020 target estimate of 80% for both outcomes. Significantly, smaller percentages of adults with an epilepsy history reported good or better physical health than adults with heart disease, cancer, or hypertension. Significantly, smaller percentages of adults with an epilepsy history reported good or better mental health than

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adults with all other four conditions. In addition, people with epilepsy showed a lower life expectancy in comparison to the general population, having an increased risk from two to three times higher for premature death [12,13]. Sudden death is approximately 20 times higher in this population [14].

Despite the technological advances in neuroimaging exams and several attempts from the *International League Against Epilepsy* (ILAE) to improve the classification of epileptic seizures and epilepsy [6,15,16], studies describing this population are scarce [17], mainly in countries of low and middle income where 80% of this population reside [18]. Considering the above information, more studies are needed describing these individuals in order to have a general view of their life and health conditions aiming at creating more precise public policies.

In this sense, the present study aimed to describe the socio-demographic, clinical, behavioral, nutritional, and health-related variables from individuals diagnosed with epilepsy.

2. Methods

This is a cross-sectional study carried out in Pelotas, southern Brazil. Pelotas is a medium-sized city (343,651 inhabitants, with 23,025 residents in rural areas) in a relatively affluent area in southern Brazil. Its economy is based on services and food industries, and its average monthly wage was 2.8 minimum wages in 2016 (R\$ 2206.00 Brazilian Reais or US\$ 690.00) [19].

The present study used a sample of 101 individuals ranging from 12 to 75 years old diagnosed with epilepsy and who attended the Neurology and Neurodevelopment Clinic from the Medicine Faculty at the Federal University of Pelotas (UFPEl). This is the only neurology clinic working for the Unified Health System and data collection took place from 1st of December 2015 to the 30th of April 2016. The data collection was carried out by one of the researchers and a neurologist at the same time; if there was any doubt, the opinion of the neurologist prevailed. The complete procedure is described in Häfele et al. [20]. The study was submitted to the ethics committee for human beings at The Physical Education Faculty/UFPEl, and it was approved under the protocol number 1.231.971.

2.1. Variables

Table 1 presents a summary of the variables and their operationalization (Table 1). The Physical Activity Questionnaire for Adolescents (PAQA) [21] and The International Physical Activity Questionnaire (IPAQ) – long version [22] were used to measure physical activity levels from adolescents and adults, respectively. The International Physical Activity Questionnaire measures physical activity levels from a normal week in the following domains: household, leisure, commuting, and work-related. However, the present study has used only the leisure and commuting domains as domestic and work-related domains seem to be overestimated [23]. In addition, this study has used a dichotomous physical activity variable (active and inactive) in the leisure and commuting domains. In order to calculate the score for de IPAQ domains, minutes for vigorous physical activity were multiplied by two; the same happened in relation to PAQA, where sports were considered vigorous physical activity and as a result, the reported time was also multiplied by two. According to the World Health Organization, adolescents should present at least 300 min/week of physical activity, and adults should present 150 min/week of physical activity to be considered active [24].

The variables sex and race/ethnicity were determined by the interviewer himself, and weight and height were self-reported. Income was determined using the following questions: 1) adolescents (12–17 years) – what is the monthly income of the family's breadwinner?; 2) adults (18 years or older) – what is your monthly income? The variable type of seizures, etiology, and seizure classification

Table 1
Description of the variables and their operationalization.

Variables	Operationalization
Sociodemographic	
Sex	Male; female
Age	12–17; 18–39; 40–59; 60–80
Race/ethnicity	White; Black; Brown
Marital status	Single; married; widow/er; divorced
Schooling	Completed years
Number of children	0; 1; >2
Income	Monthly income
Profession	Open question
Welfare	Open question
Clinical	
Seizures type	Open question
Etiology	Idiopathic/genetic; symptomatic/structural-metabolic or unknown
Antiepileptic drug (AED) use	Yes; no
Time of utilization AED	Months
Age of the first seizure	Completed years
Date of the previous seizures	Day; month; year
Age at diagnosis	Completed years
Family history	Yes; no
Total number of seizures during the life	Total number of seizure during the life
Higher frequency of seizures during the life	Completed years
Type of treatment	Monotherapy; polytherapy
Active epilepsy	Seizures in the previous 2 years
Seizures control	Controlled; not always controlled; not controlled
Other diseases	Yes; no
If yes, which disease	Open question
Other medications	Yes; no
If yes, which medication	Open question
Nutritional	
Body mass index	Weight/height ²
Health-related	
Self-perceived health	Excellent; very good; good; bad; very bad
Depression	NDDI-E
Anxiety	STAI-E-6; STAI-T-6
Side effects from AED	AEP; ≥45 points, <45 points
Stress	PSS
Quality of sleep	PSQI
Behavioral	
Smoking	Never smoked; former smoker; smoker
Alcohol intake	Never drank; drank; drinks nowadays
Main reason to practice PA	Medical prescription; personal choice; important to health; it is necessary or another reason

Antiepileptic drug (AED); physical activity (PA); Neurological Disorders Depression Inventory for Epilepsy (NDDI-E); State-Trait Anxiety Inventory (STAI), short version; Adverse Effects Profile (AEP); Perceived Stress Scale (PSS); Pittsburgh Sleep Quality Index (PSQI).

came directly from clinic records. Questionnaires previously validated to assess the following variables were used:

- Quality of life – This was measured using the Quality of Life in Epilepsy Inventory – 31 (QOLIE-31) instrument (adults) [25] and Quality of Life in Epilepsy Inventory – 48 (QOLIE-AD-48) instrument (adolescents) [26]. The QOLIE-31 is made up of 31 questions distributed among seven domains: general quality of life, seizures concerns, emotional well-being, energy and tiredness, cognitive function, social functioning, and medication side effects. Considering QOLIE-AD-48 which is made up of 48 questions divided among the following eight domains: epilepsy impact, memory and concentration, attitudes related to epilepsy, physical functioning, stigma, social support, school behavior, and perceived health. Both instruments generate a continuous total score ranging from 0 to 100; the higher the score, the better the quality of life is. In this study, only the total score was used for both questionnaires.
- Medication side effects: The Adverse Effects Profile (AEP) scale, made up of 19 questions which were answered using the Likert

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