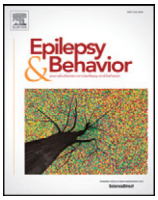
Epilepsy & Behavior 74 (2017) 45–58

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh



Factors affecting quality of life in Hungarian adults with epilepsy: A comparison of four psychiatric instruments

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ARTICLE INFO

Article history:
Received 10 February 2017
Revised 30 March 2017
Accepted 22 April 2017
Available online 5 July 2017

Keywords:
Epilepsy
Life quality
Qolie-31
WHOQOL-5
Diener SwLS
IPQ

ABSTRACT

Purpose: We investigated the impact of 19 factors on life quality in Hungarian patients with epilepsy. Wellbeing was evaluated by several inventories to investigate the impact of factors in more detail.

Methods: A cross-sectional study was performed in 170 patients. Wellbeing was evaluated with the WHO-5 Well-being Index (WHOQOL-5), Diener Satisfaction with Life Scale (SwLS), and the Quality of Life in Epilepsy-31 Questionnaire (Qolie-31). We investigated their association with demographic characteristics, general health status, epilepsy, and its treatment. The impact of these factors on illness perception (Illness Perception Questionnaire, IPQ) was also studied.

Results: The four measures correlated highly significantly. In addition, the predictive power of factors was comparable with the four inventories as evaluated by Multiple Regression. Factors explained 52%, 41%, 63% and 46% in the variance of WHOQOL-5, SwLS, Qolie-31, and IPQ scores, respectively. However, associations with particular factors were instrument-specific. The WHOQOL-5 was associated with factors indicative of general health. SwLS scores were associated with health-related and several demographic factors. Neither showed associations with epilepsy-related factors. All four categories of factors were associated with Qolie-31 and IPQ scores. Factors had an additive impact on IPQ, but not on Qolie-31.

Significance: Our findings reveal interactions between the method of life quality assessment and the factors that are identified as influencing life quality. This appears to be the first study that analyses the factors that influence illness perception in epilepsy patients, and suggests that the IPQ may become a valuable tool in epilepsy research.

1. Introduction

Epilepsy affects a relatively small proportion of the society but is highly debilitating for those affected [1]. The symptoms of the disease can relatively be well managed but epilepsy per se cannot be eliminated, and affects the quality of life even when seizures are mostly eliminated [2]. As such, understanding the factors that predict quality of life in epilepsy is essential for developing improved strategies for the management of the disease.

The spectrum of factors that can influence quality of life in epilepsy is extremely wide and includes demographic characteristics e.g. age, gender, education [3–5], indicators of general health status e.g. comorbid somatic or psychiatric conditions [6,7], and the level of control over the disorder e.g. the severity and frequency of seizures as well as therapeutic issues [8–10]. However, conflicting findings are frequent. For instance, female gender was found to be associated with better quality of life in epilepsy in some studies, with poorer life quality in others, whereas other studies observed no gender differences [3,6–7]. Similarly, low education had an influence on life quality in some [5,11,12], but not in

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Abbreviations: AED, Antiepileptic Drug; CARB, carbamazepine; CLON, clonazepam; HADS, Hospital Anxiety and Depression Scale; HADS-A, Hospital Anxiety and Depression Scale-Anxiety subscale; HADS-D, Hospital Anxiety and Depression Scale-Depression subscale; IPQ, Illness Perception Questionnaire Revised; LAMO, lamotrigine; SWLS, Diener Life Satisfaction Scale; QOLIE-10-31-89, Quality of Life in Epilepsy, 10-31-89-item scales; VALP, valproate; WHOQOL-5, WHO-5 Well-being Index.

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http://dx.doi.org/10.1016/j.yebeh.2017.04.035
1525-5050/

other studies [13–15]. Such examples are abundant; consequently, the number of factors affecting quality of life is large when these are listed based on individual reports, whereas factors considered reliable are much less in number when such studies are crosschecked [2]. One possible explanation for such inconsistencies – beyond attributing them to chance – is that the importance of particular factors is culture-dependent [1]. However, the reasons of discrepancies remain still poorly understood. One can assume for instance that the instrument used in life quality assessments may also affect the outcome of such studies. Until 2011, 16 different life quality measures were employed in epilepsy (all variants of Qolie being considered as one) [2], and their number may have increased ever since. Conflicting findings like those briefly mentioned above may be explained by such methodological differences.

Albeit contrasting findings were also reported when studies used the same life quality evaluation tool, one can still assume that the factors that affect quality of life in epilepsy may be better understood if several instruments were employed in parallel. We hypothesized that the instrument used has an impact on the possibilities of identifying factors relevant to wellbeing, and explored this hypothesis by administering four different instruments to the same patients. This approach is not entirely new [16,17], but the issue has never been systematically investigated. In the present study we compared four inventories, particularly the WHOQOL-5, SwLS, QOLIE-31 and IPQ. The WHOQOL-5 and SwLS are non-epilepsy related measures of life quality, which nevertheless are sensitive to general health-related and demographic factors [18]. The QOLIE-31 is specially designed to measure life quality in epilepsy. The IPQ on its turn is not a life quality measure, but it investigates the patients' perception of the disease with clear indications on their perceived wellbeing. This instrument was frequently used with other diseases. To our best knowledge, however, individual factors affecting IPQ scores have not been investigated so far in epilepsy patients.

The factors to be studied in relation with these measures were selected based on earlier studies as shown in the Materials and methods section. We hypothesized that the constellation of factors that affect life quality is specific to the instrument by which life quality is assessed. We also hypothesized that the very same factors will have a large impact on illness perception, which is highly relevant for, and in fact indirectly characterizes life quality. The management of life quality is a critical issue in epilepsy that goes beyond the medical effectiveness of treatments (see above). The comparative evaluation of various measures may help elaborate better ways of addressing this issue. E.g. the putative factor-specificity of various measures may be used to increase focus in life quality evaluations. In addition, the putative usefulness of IPQ may contribute to the optimization of clinical care based on the perceptions of patients per se.

2. Materials and methods

2.1. Participants and study design

We performed a cross-sectional study in 170 subjects recruited for the study from the ambulatory patients of the National Institute of Clinical Neurosciences, St. John's Hospital, and two private clinics, all being situated in Budapest, Hungary. Recruitment was randomly performed between 09.01.2011 and 30.05.2015. The following inclusion and exclusion criteria were employed. *Inclusion criteria*: specialist-diagnosed epilepsy for at least a year; age of 18–70 years; completed primary school; regular participation at periodic medical monitoring; no surgical intervention for epilepsy; symptoms controlled with AEDs; informed consent to participation in the study. *Exclusion criteria*: serious chronic disease other than epilepsy; condition that requires hospitalization; alcohol or drug dependence; evidence of non-epileptic seizures.

The study was approved by the Scientific and Research Ethics Committee of the Medical Research Council (ETT-TUKEB, Budapest, Hungary; registration No. 25962-0/2010/1018EKU (1010/PI/10; date: 24 January 2011), and was carried out in accordance with the Declaration of Helsinki and applicable Hungarian legislation on research on human subjects and medical data protection. All patients gave their informed consent for participation in the study. The characteristics of the study population were summarized in Table 1.

2.2. Data collection

Patients were asked about their age, gender, marital status, number of children, residence, education, smoking and alcohol consumption habits, stressful life events, and sleep patterns upon their arrival to the hospital for the regular monitoring of their health status (between 8 and 12.am.). They were also asked for the frequency of their seizures as well as whether seizures awaken them from sleep. Disease-related details e.g. the duration of epilepsy, seizure type, and data on other diseases as well as medications received were extracted from the medical records of patients. Smoking and alcohol consumption habits were evaluated by 4 and 5-item Likert-like scales. The items of the smoking scale were: no smoking, 1–10 cigarettes, 11–20 cigarettes, or more than 20 cigarettes per day. For alcohol consumption habits, patients had to indicate whether they do not consume alcohol, consume small amounts and rarely, little amounts but regularly, large amounts but rarely, or regularly and in large amounts. Stressful life events asked for included the loss of loved ones, divorce or breakup, serious accidents, loss of job, serious financial losses, and others. Regarding sleep, we recorded its duration (4, 5, 6, 7, 8, or more hours), and its quality on a 5-item Likert-like scale (very poor, poor, average, good, very good). We used 4-item Likert-like scales for assessing difficulties falling asleep and awakening by seizures (every night, most nights, some nights, never). The frequency of seizures was investigated by a 7-item scale ranging from daily seizures to one seizure every 3–4 years or less. After recording these data, patients were asked to fill in psychometric instruments.

2.3. Psychometric instruments

Diener Life Satisfaction Scale (*SWLS*). This is a 5-item self-assessment questionnaire that evaluates subjective well being (Diener et al., 1985). Respondents indicate on a seven-point-scale how much they agree or disagree with each of the 5 items. The item scores are added, giving total scores from 5 to 35. We used the validated Hungarian version [19].

Table 1
The characteristics of subjects.

Age (mean ± SD, years)	36.92 ± 12.33	Years with epilepsy (%)	
Gender (%)		1	6.1
Male	41.8	2–5	14.1
Female	58.2	5–10	18.2
Marital status (%)		10–15	8.8
Single	44.7	15 +	49.4
With spouse	55.3	Type of seizure (%)	
Children (%)		Partial	63.1
0	53.9	Generalized	36.9
1	25.7	Seizure frequency (%)	
1 +	20.4	One/3–4 years	22.2
Residence (%)		One/3–6 month	23.6
Urban	86.4	Monthly	42.2
Rural	13.6	Weekly/Daily	9.9
Education (%)		Therapy (%)	
Primary/vocational	28.7	Monotherapy	30.0
High school	40.4	Polytherapy	70.0
College/University	29.9	Smoking (%)	
Employment (%)		No	80.0
Employed/Student	59.4	Yes	20.0
Disabled	25.2	Alcohol consumption (%)	
Unemployed	7.4	No	66.1
Dependent/retired	7.9	Yes	43.9