



## Patient and caregiver quality of life in psychogenic non-epileptic seizures compared to epileptic seizures



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### ABSTRACT

**Purpose:** Little is known about the effect of psychogenic non epileptic seizures (PNES) to caregiver quality of life (QOL), particularly as it compares to epileptic seizures (ES). We sought to characterize this effect and identify its determinants.

**Methods:** The study population comprised of 126 ES and 33 PNES patients who underwent video EEG monitoring along with 48 and 18 caregivers respectively who accompanied them to their investigations. Patients completed questionnaires providing demographic, disease-related, cognitive, psychiatric, sleep and QOL information on admission, prior to their diagnosis being clarified. Their caregivers completed questionnaires providing demographic, disease burden and generic QOL information. Paraclinical data were also gathered. Regression analysis was used to identify patient and caregiver related determinants of patient and caregiver QOL.

**Results:** QOL scores were significantly worse for PNES than ES patients and were mainly linked to depression levels. PNES and ES caregivers had comparable demographic characteristics and QOL scores. ES caregiver QOL was better in employed caregivers with lower burden scores for the physical component summary (PCS) and worse in female caregivers of depressed patients with higher burden scores for the mental component summary (MCS). Caregiver burden score was the strongest correlate of PNES caregiver MCS QOL score.

**Conclusion:** Caregiver QOL in PNES does not differ from caregiver QOL in ES, while patient QOL is worse in PNES. Caregiver burden emerges as a consistent correlate of caregiver QOL both in ES and PNES. These findings advocate for consideration of caregiver burden and QOL in PNES in clinical practice and for future research paradigms.

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## 1. Introduction

Clinical behavior in psychogenic nonepileptic seizures (PNES) resembles epileptic seizures (ES) without an electrographic correlate and has a strong psychological basis.<sup>1</sup> PNES constitute 10–30% of referrals to epilepsy specialists,<sup>2,3</sup> with their prevalence in the general population being estimated at 2–33 per 100,000,<sup>3</sup> generating a significant public health problem with an estimated lifetime cost per patient cohort year in the US ranging from \$110 to 920 million.<sup>4</sup>

In addition to the society, PNES take a significant toll on the individual patient. Quality of life (QOL) in patients with PNES has been consistently shown to be worse than in patients with epileptic seizures (ES).<sup>5</sup> Despite their significant impact on their bearers, our understanding of PNES pathophysiology is limited and hence optimal approach to management remains elusive.<sup>6</sup> A number of interventions have been proposed, which are not limited to pharmacotherapy, cognitive-behavioral therapy, psychodynamic, psychotherapy, hypnosis and group therapy.<sup>7</sup> These treatments predominantly target the patient,<sup>8</sup> typically use seizure frequency as the primary endpoint,<sup>6</sup> have limited generalizability<sup>9</sup> and have yielded overall poor outcomes.<sup>10,11</sup>

More recently, LaFrance et al. elegantly explored the role of family dysfunction as a potential contributor to poorer QOL in patients with PNES and subsequently, as a potential foothold for

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intervention.<sup>12</sup> QOL was examined from the patient but not from the caregiver perspective. The primary aims of this study are (i) to characterize caregiver QOL in PNES and (ii) to identify which patient and caregiver related factors determine it. As a secondary aim, we use a comparison group of patients/caregivers with ES and attempt to ascertain how patient and caregiver characteristics, QOL scores and QOL determinants differ between the two populations. We subsequently discuss clinical and research repercussions of our findings.

## 2. Methods

### 2.1. Participants

The study was approved by the institutional review boards of the participating hospitals. This cross-sectional study was conducted between September 2009 and June 2011 at Massachusetts General Hospital (MGH) and Boston University Medical Center (BUMC). Adult patients admitted electively to Epilepsy monitoring units at in those two sites for continuous video-EEG monitoring were asked to participate by completing a series of questionnaires and undergoing bed-side cognitive evaluation. Patients who were non English speakers or unable to read and write due to mental handicap were excluded. Caregivers who accompanied them were also asked to complete questionnaires. Caregiver was defined as the family member who was primarily responsible for providing every-day care for the patient. After monitoring was completed, patients were classified as ES vs PNES based on video-EEG criteria. Only patient with documented ES (80 at MGH and 46 at BUMC) and PNES (31 at MGH and 2 at BUMC) along with their respective caregivers (48 for ES and 18 for PNES, all at MGH) were included in the analysis, while patients with other non-epileptic seizures (e.g. cardiac arrhythmias, sleep or movement disorders, etc.), mixed disorder or unclear diagnosis were excluded along with their caregivers.

### 2.2. Questionnaires and procedures

Participating patients completed questionnaires providing demographic (age, gender, race, religion, employment, education, living situation and marital status) and epilepsy related (age of disease onset, disease duration, average number of seizures/spells per month in the past year, number of AED, compliance) information. Additional information collected was gleaned from medical records review. Anxiety and depression levels were measured using the Beck anxiety<sup>13</sup> and Beck depression<sup>14</sup> inventory respectively. Both have been extensively used previously in research for ES<sup>15</sup> and PNES.<sup>12</sup> Sleep quality was assessed by completing the Epworth sleeping scale<sup>16</sup> and the sleep apnea section of the sleep disorder questionnaire (SDQ-SA).<sup>17</sup> While not specific to patients with epilepsy, the Epworth sleeping scale has been widely used to assess sleepiness in a host of diseases including epilepsy.<sup>18</sup> The SDQ-SA has also been commonly applied to the epilepsy population.<sup>19</sup> Quality of life was evaluated by completing the QOLIE-31 instrument. QOLIE-31 is one of the most commonly applied QOL instruments in epilepsy with good reliability and validity.<sup>20</sup> It has been previously used for evaluation of QOL in PNES, given the shared concerns by both groups of patients, both in this abbreviated form<sup>21</sup> as well as in its original version (QOLIE-89).<sup>10</sup> Cognitive evaluation was performed by a neurologist via administration of the Montreal cognitive assessment (MoCA) test.<sup>22</sup> This is a brief screening tool that has been shown to be superior to the commonly used mini-mental status examination for the detection of mild cognitive impairment in the epilepsy population.<sup>23</sup> All these evaluations took place on the day of the admission under electrographic guidance to ensure the absence of subclinical electrographic seizure activity affecting

some of the responses. At the time of the testing, the patients were maintained on their home AED(s) and had not been yet sleep deprived with the intent that their answers would be representative of their baseline state in the ambulatory setting. They were also not aware yet of the final EMU diagnosis.

Caregivers accompanying the patients also completed questionnaires prior to establishing the final EMU diagnosis. The questionnaires included several demographic information (age, gender, race, religion, employment, education, marital status, cohabitation and time spent for patient care in hours per week). The latter was loosely defined as the time devoted to everyday activities where caregiver participation was indispensable including AED provision, outpatient and emergency department visits and driving for any patient-related activity. Given the lack of a disease specific questionnaire to assess their burden, the Zarit caregiver burden inventory was used instead. This is a 22-item inventory derived from the original 29-item inventory.<sup>24</sup> It is the most widely used standardized, validated scale to assess caregiver burden, administered previously in various neurological disorders, including epilepsy.<sup>25,26</sup> Caregiver health-related quality of life was assessed by administering the second version of the SF-36 generic questionnaire (SF36v2).<sup>27</sup> This is a generic QOL instrument that assesses eight health concepts. Scores standardized to norms and weighted averages are used to create a summary physical component summary (PCS) and a mental component summary (MCS) composed by the first and last four of the aforementioned health concepts respectively. Scores are standardized to norm and this allows direct comparison among different populations<sup>27</sup>; thus it has established precedence in epilepsy caregiver research. Various paraclinical (laboratory, electroencephalographic and radiologic) data were collected as part of standard of care. Routine AED levels were drawn on admission prior to initiation of gradual withdrawal. For patients on more than one AED, they were deemed to be suprathreshold, therapeutic or subtherapeutic on their regimen depending on the level of the majority of drugs in their regimen. EEG data pertained to the initial recording during the completion of the questionnaires (normal, slow, epileptiform) including the maximal posterior dominant rhythm at the time of completion and the final EMU report for classification to the ES vs PNES category. Radiological data included findings of the last patient's brain magnetic resonance imaging (normal vs abnormal) obtained before, during or right after this monitoring.

For a detailed description of the questionnaires used both for patients and caregivers, please refer to the [Appendix](#).

### 2.3. Analysis

Summary scores were created for all the aforementioned variables and descriptive statistics were used. Univariate comparisons for demographic variables between the ES and PNES patients and between the ES and PNES caregivers was performed using *t*-test (or non-parametric equivalent) for continuous variables respectively and Chi-square test for categorical variables. The outcome variable of interest was QOLIE-31 score for ES and PNES patients and SF-36v2 (PCS and MCS separately) scores for ES and PNES caregivers. For QOL of ES and PNES patients, only patient related characteristics were used as covariates. For QOL of ES and PNES caregivers, both patient and caregiver related characteristics were used as covariates. Univariate associations between the outcomes of interest and their potential determinants were explored by using *t*-test or one-way ANOVA for categorical variables and Pearson correlation for continuous variables. Statistical significance was set at 0.05. Those variables identified as statistically significant in the univariate analysis were subsequently fitted in a multivariate linear regression model in order to conduct an adjusted evaluation of QOL determinants.

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