



Quality of life and level of burden in primary caregivers of patients with epilepsy: Effect of neuropsychiatric comorbidity

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ABSTRACT

Background: Few studies are focused on the quality of life (QOL) of primary caregivers and the effects of the clinical variables of epilepsy and patient psychiatric comorbidity on primary caregivers.

Purpose: Our main objective was to describe QOL and level of burden (LB) in caregivers of people with epilepsy (PWE) at a tertiary-care hospital in Mexico City. A secondary purpose was to determine if LB and QOL were different between caregivers of patients with neuropsychiatric comorbidity and caregivers of patients without neuropsychiatric comorbidity.

Methods: One hundred and fifty-one caregivers of PWE were assessed with the short version of the World Health Organization Quality of Life (WHOQOL) scale (WHOQOL-BREF) and the Zarit Burden Interview. Patients' clinical and demographic data, along with their psychiatric histories, were collected.

Results: One hundred and twelve patients had psychiatric comorbidity. The mean LB score of the caregivers was 26.25 ± 16.28 . The mean scores for the WHOQOL-BREF domains were as follows: physical health, 47.8 ± 10.7 ; psychological health, 55.4 ± 11.5 ; social relationships, 47.23 ± 18.6 ; and environment, 48.7 ± 11.6 . The caregivers of patients with psychiatric comorbidity had lower scores in the domains of psychological health ($p = 0.034$) and social relationships ($p = 0.029$) compared with caregivers of PWE without comorbidity. On adjusted multivariate analysis, aggressiveness ($p = 0.008$), age at onset of epilepsy ($p = 0.02$), and years with epilepsy ($p = 0.01$) were associated with higher caregiver LB scores; higher caregiver years of education were associated with better psychological health ($p = 0.002$) and more years with epilepsy ($p = 0.03$) with lower QOL scores.

Conclusion: Aggressive behavior was the psychiatric comorbidity most clearly associated with lower QOL and higher LB. Longer duration of epilepsy was related to higher burden and lower QOL. More years of education of the caregiver were associated with better QOL. We found no significant correlation between seizure control and QOL or LB.

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1. Introduction

Epilepsy is a major health problem worldwide [1,2] because it imposes a degree of burden [3] on the individuals who have it and also because these individuals' suffering and disabilities affect their family and their society [4,5]. Because of the direct neurological effects of the disease, the side effects of antiepileptic drugs (AEDs), and psychosocial repercussions (disability, stigma, and other negative factors) [6,7], people with epilepsy (PWE) are more prone to psychiatric conditions [8–12], which are often more stigmatized than the epilepsy itself [8] and which further decrease their quality of life (QOL) and that of their

caregivers [9]. According to the World Health Organization (WHO), the primary caregiver is the person in the patient setting who voluntarily assumes the role of caregiver in a broad sense and is willing to make decisions for the patient and to cover the patient's basic needs directly or indirectly [10]. Through the simple act of caring and being responsible for another person, caregivers may come to experience a degree of burden, which is defined as a multifactorial construct that includes emotional, psychological, physical, and financial aspects along with related feelings such as shame, grief, anger, and guilt. The level of burden (LB) is classified as either objective (which refers to changes in the routines of the home, family, social relationships, work, free time, or physical health) or subjective (which consists of fatigue, including impact on mental health) [11,12].

When LB and QOL have been studied in caregivers of PWE, most research has focused on children and adolescents [13–15]. Data on caregivers of adults are sparse [14–19].

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Level of burden in caregivers of PWE is comparable to that reported in the literature for other chronic neurological conditions [20]. A higher number of AEDs, poorer patient neuropsychological performance, lower patient QOL score, and lower caregiver education level have been associated with higher caregiver LB [20]. But how psychiatric comorbidity in PWE affects caregiver LB and QOL is an understudied subject.

Our main objective was to describe LB and QOL in caregivers of PWE at a tertiary-care hospital in Mexico City. A secondary objective was to determine if LB and QOL were different between caregivers of patients with neuropsychiatric comorbidity and caregivers of patients without neuropsychiatric comorbidity.

2. Materials and methods

A descriptive, cross-sectional, analytical study was conducted from April 6 to November 14, 2016 under the approval of the ethics and clinical research committees.

2.1. Patients and procedure

The study was conducted at the National Institute of Neurology and Neurosurgery (NINN) in Mexico City. Primary caregivers of PWE treated at the outpatient neuropsychiatry and epilepsy clinics were included. Primary caregivers of PWE were defined as persons who had been responsible for the care of a patient diagnosed with epilepsy by an epileptologist according to the criteria of the International League Against Epilepsy (ILAE), for at least one year without receiving any financial compensation for such activity. Informed consent was obtained from all participants after the procedure had been fully explained. Caregivers who were not recognized as the primary caregiver and caregivers of patients who had not experienced seizures in the previous 12 months were excluded. Participants were withdrawn from the study if they failed to respond to the scales appropriately.

2.2. Questionnaires

Patients and caregivers completed questionnaires providing demographic (age, sex, education, relationship, employment, socioeconomic status, number of caregivers) and epilepsy-related information (age at epilepsy onset, duration in years, number of seizures per month in the last 6 months, number of AEDs). The information collected was cross-validated with medical records.

A diagnosis of a psychiatric disorder was given based on physicians' notes from the previous year. Nearly all patients treated at the NINN's epilepsy clinic periodically receive a neuropsychiatric and/or neuropsychological evaluation, so missing a diagnosis of a psychiatric disorder was unlikely.

A diagnosis of a psychotic disorder was given if prominent interictal or postictal hallucinations or delusions were present (according to the Diagnostic and Statistical Manual of Mental Disorders—Fourth Edition (DSM-IV) diagnostic criteria for psychotic disorder due to a general medical condition). The presence of nonepileptic seizures, in addition to epilepsy, was established only by a diagnostic level of certainty of “probable,” “clinically established,” or “documented,” according to the diagnostic levels of certainty proposed by the ILAE Task Force [21]. The presence of aggressiveness was established when any modality of aggressive behavior was documented in the medical notes for the previous 6 months (i.e., verbal or physical aggression, self-harm, or aggression against property).

Diagnoses of major depressive disorder, intellectual disability (mental retardation), and anxiety disorder (any of the anxiety disorders) were given according to the DSM-IV criteria.

The primary caregiver was determined to be financially dependent when he or she needed the salary of another person to subsist [22].

After the initial interview, the following scales were administered.

- The short version of the World Health Organization Quality of Life (WHOQOL-BREF) [23] instrument comprises 26 items that measure the following broad domains: physical health, psychological health, social relationships, and environment. It is a shorter version of the original instrument, the WHO QOL scale, which has been validated in the Spanish language [24]. The possible scores range from 0 to 100, and higher scores denote higher QOL. The WHOQOL-BREF has been used to evaluate caregivers of patients with psychiatric or neurological comorbidities [17–20,25,26].
- The Zarit Burden Interview version validated in Spanish [27], is used to measure the burden of caregivers of chronic patients, including PWE [9]. This scale consists of 22 questions that evaluate the effects of the disease on the caregiver's QOL, psychological suffering, financial difficulty, embarrassment, guilt, and difficulties in social and family relationships. A score of less than 20 is considered little or no burden; 21–40 is moderate burden; 41–60 is moderate to severe burden; and 61–88 is severe burden (LB score) [26].

2.3. Statistical analysis

Sample size calculation was performed, taking into account the confidence interval of the mean domain value of the caregiver's QOL, using the following formula: $N = 4Z_{\alpha}S^2 \div W^2$, where W is the standard amplitude of the desired confidence interval (95%) and S is the standard deviation (SD) of the mean domain value of the caregiver's QOL. From a pilot study that we conducted (unpublished data), it was determined that the expected W with a 95% CI was 5.91, with an S of 9.45. Using the Z-tables, it was calculated that a minimum of 97 patients was required [28].

We also determined the sample size required to compare the QOL of the relatives of patients with and without neuropsychiatric comorbidities. Taking into account a standardized effect size of 5.91 and a SD of 9.45, with an α of 0.05 and a β of 0.20, 34 patients were required per group [28].

Based on the main objective of this study, measures of central tendency and proportions were used in order to describe the clinical and sociodemographic characteristics of the patient and his/her caregiver and to report the scores for the Zarit scale and the QOL instrument.

To compare QOL and burden between caregivers of patients with psychiatric comorbidity and caregivers of patients without neuropsychiatric comorbidity, an independent samples t-test was performed (or the Wilcoxon signed-rank test for non-normal distributions). Psychiatric comorbidity subgroups were compared using analysis of variance (ANOVA).

A Pearson's correlation analysis was performed between the main dimensional variables. Variables identified as statistically significant in the univariate analysis were fitted in a multivariate linear regression model in order to perform an adjusted evaluation of LB and QOL determinants.

3. Results

3.1. Description of the sample

Two hundred and ten patient–caregiver pairs were invited to participate; 41 were excluded because of incomplete information, and 18 declined to participate. Thus, 151 pairs were included. The sociodemographic characteristics of the patients are described in detail in Table 1. Mean patient age was 34.8 ± 11.68 years, the average number of seizures per month was 8.2 ± 16.40 , and 79% ($n = 72$) of the patients had had at least one seizure in the previous 6 months. The characteristics of the caregivers are described in Table 2. The majority of caregivers were women, with a mean age of 52 ± 11.88 years, generally a complete secondary education, and low socioeconomic status.

Although 51% of the caregivers reported working outside the home, 70% needed financial support from others.

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