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Quality of life and Stigma in Lebanese People with Epilepsy Taking Medication

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Abstract

Background: Epilepsy is among the more stigmatising diseases, leading to a negative impact on the quality of life (QoL) of people with epilepsy (PWE). Assessment of the QoL and stigma in PWE reflects the outcome of their disease, and the findings can be used to improve the management of epilepsy. To fill a gap in the literature, our primary aim is to evaluate the QoL and stigma in Lebanese PWE, and our secondary aim is to identify factors affecting these parameters.

Material and Methods: A cross-sectional study was conducted for 1 year in Greater Beirut. PWE were interviewed by using a standardised questionnaire. QoL was evaluated by the QoL in Epilepsy Inventory-10 (QOLIE-10), and the stigma was evaluated by the Jacoby scale. Multivariate analyses were used to identify the factors associated with QoL and stigma.

Results: The sample was 404 PWE. More than half of the PWE (61.4%) had a better QoL than the other PWE (mean QOLIE-10 score of 26.9 ± 11.3), and 47.8% of PWE felt stigmatised. Linear regression showed that presence of psychiatric comorbidities ($p=0.03$), stigma ($p<0.001$), experiencing side effects ($p=0.001$), polytherapy ($p=0.002$), living in a northern area ($p=0.003$), and older age ($p=0.004$) were the major factors associated with a poor QoL. Logistic regression showed that a low level of QoL ($p=0.005$) and experiencing side effects ($p=0.045$) were associated with a high level of stigma.

Conclusions: An appropriate treatment based on a monotherapy can reduce the risk of side effects, improving QoL of PWE, and decreasing stigma. Furthermore, the management of depression by specialists is an essential step to improve the QoL of Lebanese PWE. Education programmes and information on epilepsy and treatment also play a major role in reducing stigma.

Keywords: Epilepsy; Antiepileptic drugs; Quality of Life; Stigma; Lebanon.

1. Introduction

Epilepsy is a neurological disorder that affects more than 70 million people worldwide, of whom 80% reside in developing countries (Ngugi et al., 2010). This disorder is one of the most important public health problems, which affects people with epilepsy (PWE), their families, and society (Boling et al., 2018). This disease is characterised by unpredictable symptoms, such as a loss of consciousness, and is associated with considerable psychological consequences (Hermann and Jacoby, 2009), which can prevent PWE from driving, getting married, or employment, because of the risk of seizure (Boer et al., 2008). These consequences negatively affect the quality of life (QoL) of PWE (Jacoby et al., 2005) and can lead to their stigmatisation (Loring et al., 2004). Improving QoL is one of the goals of epilepsy management (Perucca and Tomson, 2011; Privitera and Ficker, 2004). Assessment of QoL is a means to identify the severity of seizures (Vickrey et al., 2000) and evaluate the effect of anti-epileptic drugs (AED; Birbeck et al., 2007; Gilliam et al., 2004; Melikyan et al., 2012).

Studies have demonstrated that QoL is lower among PWE compared to the general population (Villeneuve, 2004). In Europe and North America, PWE had a poor QoL (Buck et al., 1999; Stavem et al., 2000). Despite the data indicating a high prevalence of PWE in Africa (Meinardi et al., 2001), few studies have been published on the QoL in these populations (Mrabet et al., 2004). In the Arab world, a low QoL score has been detected in most studies (Al-Khateeb and Al-Khateeb, 2014). Socio-demographic and clinical factors affect the QoL of PWE and increase the stigma (Baker et al., 1997; Sanyal and Roy, 2004).

Notably, the psychosocial consequences of epilepsy increase the risk of stigma, leading to the social isolation of PWE (Loring et al., 2004). Stigma is divided into felt and enacted stigma (Jacoby, 2008). Enacted stigma refers to acts of discrimination by the public against PWE

because of their perceived inferiority (Jacoby, 1994). Felt stigma is the self-stigmatisation of PWE related to shame and fear of discrimination (Jacoby, 2008, 1994). Many studies have indicated that 50% to 70% of PWE feel stigmatised (Lee et al., 2016; Luna et al., 2017; Sleeth et al., 2016). Social stigma of PWE has occurred in developed and developing regions (Baker et al., 2005; Guekht et al., 2007). Insufficient information about epilepsy leads to stigma (Zanni et al., 2012), contributes to hiding the disease, and decreases medication adherence (Inzlicht et al., 2006). The perceptions and knowledge of PWE regarding their disease play an additional role in the evaluation of the consequences of epilepsy on their daily functions (Cramer et al., 1996). Psychiatric comorbidities, including anxiety and depression, are more frequent in PWE who felt stigmatised (Leaffer et al., 2014; Wang et al., 2015). The factors contributing to a stigma vary by country and culture, for example, seizure severity, social support, QoL, and depression (Benson et al., 2016; Leaffer et al., 2014; Smith et al., 2009).

In the Arab region, stigma is among the main psychosocial problems of PWE, who have low overall QoL scores (Al-Khateeb and Al-Khateeb, 2014). In a study of 10 Middle East regions in 2005, including Lebanon, QoL was evaluated by using 36-Item short-form survey (SF-36) (Baker et al., 2005); however, data on the level of QoL and factors affecting this QoL of Lebanese PWE were absent. Information regarding QoL and stigma in Lebanese PWE is limited. Due to this knowledge gap, this study's primary and secondary aims are to evaluate QoL and stigma in Lebanese PWE and identify the factors affecting these parameters, respectively.

2. Materials and method

2.1. Study design

A cross-sectional study was conducted between January 15, 2018, and January 15, 2019, in Greater Beirut (Beirut City and suburbs; Figure 1). For 1 year, 35 neurologist's clinics (private, hospitals, and medical centres) were visited by an investigator to recruit PWE from different Lebanese regions.

2.2. Study population

The estimated minimal sample size was 384 patients, using 95% as the confidence interval (CI), 5% for precision error (Charan and Biswas, 2013), and 50% as the estimated percentage of PWE who were having a better QoL and not stigmatised, because of a lack of data in the literature.

Lebanese PWE aged 18 years and above, diagnosed as epileptic for at least 1 month by a neurologist, and consenting to participate were included. The exclusion criteria were mental retardation or intellectual disability (based on medical history in medical records), which can limit communication, and being. Because there are no medical records for refugees in Lebanon, and the health care services available to them are limited and difficult to access, the refugees in Lebanon were also excluded.

2.3. Data collection

A 15-minute face-to-face interview, that used the standardised questionnaire for investigation of epilepsy was conducted with PWE (Preux, 2000).

The questionnaire had six parts:

- Socio-demographic characteristics: age, gender, region of residence, habitat, marital status, education level, profession, number of persons who work per family, and monthly income.

- History of epilepsy: duration of disease, age of epilepsy onset, presence of active epilepsy (defined by the presence of seizures in the last 5 years), controlled epilepsy (no seizure in the last 6 months) (Ferrari et al., 2013; Smithson et al., 2013)), seizure type (simple partial/focal, complex partial/focal, tonic clonic, myoclonic, atonic, absence), epilepsy aetiology (symptomatic/structural-metabolic, idiopathic/genetic, cryptogenic/unknown) (Fisher et al., 2017; Scheffer et al., 2017).

- Treatment and health status: type and number of AED, side effects of AED (e.g. tiredness, agitation, nervousness, headache, memory problems, tremor, disturbed sleep, disturbed vision, rash, weight gain/loss, upset stomach), and presence of comorbidities (presence of one or more chronic diseases other than epilepsy).

- Compliance with AED was evaluated by the 4-item Morisky Medication Adherence Scale (MMAS-4) (Morisky et al., 1986).

- QoL was evaluated by the QOLIE-10 (Cramer et al., 1996).

- Stigma was evaluated by the Jacoby scale (Jacoby et al., 1996). Questions that may be related to stigma were added: what causes epilepsy; is epilepsy contagious; can epilepsy be treated; and does the respondent receive advice, participate in social activities, and discuss their epilepsy with others.

Based on medical records, history of epilepsy, treatment, and health status were extracted from each medical file.

According to recommendations on the evaluation of QoL, the part concerning QoL was administered to PWE before the consultation in a private setting (Baker, 2001).

2.4. Measuring instruments and assessment criteria

2.4.1. Medication adherence scale

The MMAS-4 is a standardised validated questionnaire to evaluate self-reported attitudes on medication. It comprises four items with four 'Yes/No' questions. This scale measures intentional and unintentional adherence: forgetting, carelessness, and stopping the drug if feeling better or worse (Morisky et al., 1986). Based on the literature (Ferrari et al., 2013; Gabr and Shams, 2015; Moura et al., 2016), a 'Yes' and 'No' answer received 0 and 1 point, respectively. The total score ranged from 0 to 4. The PWE with a score equal to 4 were adherent to AED; a score <4 was considered nonadherent.

2.4.2. QoL scale

The QOLIE-10 is one of the validated tools to evaluate QoL in PWE aged 18 years and above. It comprises 10 questions in seven categories of QOLIE-31 (Cramer et al., 1998, 1996): seizure worry, overall QoL, emotional well-being, energy/fatigue, cognitive functioning, effects of medication (mental and physical effects), and social activity (drive, work, and social limits). The responses are provided on a Likert-type style: All, most, a good bit, some, a little, and none/of the time. Three questions have opposite response sets, requiring reverse scoring. All positive responses are lower numbers, and all negative responses are higher numbers. Responses to all items were coded: the total score ranged from 10 to 51, based on the QOLIE-10 Scoring Calculator for the American Academy of Neurology (American Academy of Neurology, n.d., n.d.). A low score indicates a better QoL, and a high score indicates a poor QoL. A score between 10 and 30.5 represents a high QoL; a score higher than 30.5 reflects a low QoL (American Academy of Neurology, n.d.; Cramer et al., 1996).

2.4.3. Stigma scale

Jacoby's stigma scale was a validated scale to assess felt stigma among PWE (Jacoby et al., 1996) and comprises three questions: *Are people without epilepsy uncomfortable with PWE? Do people without epilepsy treat PWE as inferior? and Do people without epilepsy prefer to avoid PWE?* A 'Yes' response was coded 1, and a 'No' response was coded 0. The score ranged from 0 to 3. Four categories were established: no stigma (score =0), mild (score=1), moderate (score=2), and severe (score=3). The Jacoby scale has been validated and used with PWE in Lebanon, namely, one study of 10 middle eastern countries (Baker et al., 2005).

2.5. Translation of questionnaires, scales, and forms

A questionnaire comprising the three scales used in this study was translated into Arabic, the local language, to elicit questions and responses. The translation and cultural adaptation was based on the World Health Organization (who) process ("WHO | Process of translation and adaptation of instruments," n.d.): forward-translations and back-translations. A translation into Arabic was performed by two bilingual independent individuals. A comparison was performed to detect any inconsistency between the two Arabic versions. A back translation was performed by a third individual unaware of the original English version. The back-translated and original versions were compared to resolve any discrepancies. A pretest was conducted with 20 patients not included in the final sample.

2.6. Statistical analysis

Data were collected and then analysed by using SPSS version 20. Descriptive analysis was conducted by using percentage/frequency for qualitative variables and mean/standard deviation for quantitative variables. Cronbach's alpha was calculated to evaluate the reliability of each

translated Arabic scale. A value of Cronbach's alpha was greater than 0.5 for the three scales (0.73 for MMAS-4; 0.55 for QOLIE-10; 0.89 for Jacoby scale); this finding showed that the questionnaire was considered reliable.

Student t_test and one-way ANOVA were used to compare means. The chi_square and Fisher's exact test were used to compare percentages between groups. The results of univariate analysis indicated that the variables with a p_value of <0.2 should be selected for multivariable analysis. A backward linear regression was built to determine factors associated with QoL, using 'total QOLIE-10 score' as a dependent variable. A backward logistic regression was conducted to identify factors associated with stigma by using 'stigmatised: yes/no' as a dependent variable. The statistical significance of the results was determined according to 95% confidence intervals. A p_value of ≤ 0.05 was considered statistically significant throughout the study.

3. Results

3.1. Socio-demographic characteristics

This study recruited 404 PWE: male (51.2%), married (46.3%), unemployed (59.9%), and a low level of education (25.7% illiterate and 22.8% had a primary level; Table 1).

3.2. History of epilepsy and health status

Of the 404 participants, 81.4% had active epilepsy, 53.7% had uncontrolled epilepsy, 53% had symptomatic aetiology (trauma, infection), and 54.5% had comorbidities (Table 2). Focal epilepsy was the most common type in Lebanese PWE (52.2%). Depression and anxiety were the main comorbidities in one quarter of this population.

3.3. Antiepileptic medication and compliance

Sodium valproate was the most common AED prescribed in monotherapy and polytherapy (49.0%). More than one AED per day was prescribed for 42.3% of PWE. Side effects due to AED we observed in 51.0% of PWE (Table 2). Tiredness and drowsiness were the main side effects experienced by PWE. Among the 404 PWE, 141 (34.9%) were adherent to treatment (Table 2).

3.4. Levels of stigma in PWE

Among the 404 PWE, 193 (47.8%) felt stigmatised (7.2% mild, 12.6% moderate, 28.0% high stigma), and 211 (52.2%) did not report being stigmatised. The responses to each question in the Jacoby scale are presented in Table 3. The PWE who felt uncomfortable, were considered by others to be inferior, and were avoided by others, and were significantly more stigmatised (Table 3). The distribution of the stigma levels is reported in Figure 2.

3.5. QoL and factors associated

The mean QOLIE-10 score was 26.9 ± 11.3, ranging from 10 to 51. The majority of PWE (61.4%) had a high QoL (score < 30.5); however, almost one third had a low QoL (score > 30.5). The linear regression showed that PWE who worked (Beta = -3.47, p=0.001), who lived in the south (Beta = -2.85, p=0.05), and who had controlled epilepsia (Beta = -2.24, p=0.02) were associated with a low QOLIE-10 score (i.e. a better QoL; Table 4).

However, a stigma and living in the north significantly increased the QOLIE-10 score (Beta = 8.38, p<0.001 and Beta = 11.16, p=0.003). Furthermore, presence of psychiatric comorbidities (Beta = 2.25, p=0.03), experiencing side effects (Beta = 3.12, p=0.001), polytherapy (Beta =

242 3.01, p=0.002), andolder age (Beta = 0.09, p=0.004) were associated with a high QOLIE-10
243 score (i.e. a poor QoL; Table 4).
244
245 **3.6. Factors associated with stigma**
246 The majority of the 404 PWE knew that epilepsy is a neurological disorder that can be inherited
247 (54.2%), and noncontagious disease (73.8%; Table 1). The PWE who were nonstigmatised
248 participated in social activities (84.8%) and shared aspects of their epilepsy with others (70.6%;
249 Table 5).
250 Presence of comorbidities (OR=0.4; 95%CI 0.2-0.9; p=0.02), and contact between PWE and
251 people without epilepsy to discuss epilepsy (OR=0.07; 95%CI 0.03-0.15; p<0.001) were
252 associated with a low level of stigma.
253 By contrast, a poor QoL (OR=1.05; 95%CI 1.02-1.09; p=0.005), and experiencing of side effects
254 (OR=2.02; 95%CI 1.02-4.01; p=0.045), were associated with a high level of stigma (Table 5).
255
256 **4. Discussion**
257 **4.1. Factors associated with QoL**
258 Several studies have evaluated QoL in PWE by using QOLIE-10. This scale is a reduced version
259 of QOLIE-31 and a rapid and accurate tool to apply in daily practice with PWE. It was used in
260 Arabic language and was shown to be reliable in our study.
261 The average score was 26.9 for the 10 items of the QOLIE-10. Compared to other studies based
262 on the same scoring algorithm, the mean score in this study was higher than that in India (21.4)
263 (Basu et al., 2008) and China (23.1) (Gao et al., 2014) but lower than that in the United States
264 (28.1) (Bautista et al., 2009). These results may reflect a variation in populations in different

countries due to cultural, economic, and ethnic differences, as well as contextual factors such as worldwide armed conflicts.

Based on an assessment of the QoL of PWE in 10 Middle East regions and using another scale (SF-36), Oman presented the lowest overall score; however, Bahrain, Lebanon, and Qatar presented the highest score for the main domains of SF-36 (Baker et al., 2005). In addition, an overview of studies on the QoL of PWE in Arab countries showed that the SF-36 was used in studies in Arab countries to compare the QoL of PWE and the general population as a control group (Al-Khateeb and Al-Khateeb, 2014). The results of studies conducted in nine out of the 22 Arab countries showed that the QoL of PWE was generally low (Al-Khateeb and Al-Khateeb, 2014). This scale is not specifically for epilepsy and can be used for the general population. A comparison of the results of the studies that have used other instruments to evaluate QoL was difficult.

More specifically, in Lebanon, the QoL in PWE was evaluated in specific circumstances (after surgery, after vagal nerve stimulator insertion, and after temporal lobectomy) (Mikati et al., 2010, 2009, 2008, 2006, 2004). However, in our study, QOLIE-10 was used as a specific instrument for epilepsy to evaluate QoL in Lebanese PWE in clinical settings.

Advanced age, stigma, polytherapy, side effects, living in the north, and psychiatric comorbidities were identified as factors associated with poor QoL.

Advanced age was significantly associated with a low QoL (Djibuti and Shakarishvili, 2003; Senol et al., 2007). Older people have limited physical activity, a low chance for driving or employment, are more depressed, and are more affected by the psychosocial effects of epilepsy (McLaughlin et al., 2010). Compared with older PWE, young PWE has a more active social life

and had more opportunities for employment, and this might positively affect their QoL (Baker et al., 2001).

The PWE who felt stigmatised presented a poor QoL, and this finding supports those in other studies (Suurmeijer et al., 2001). Stigma was the most important factor associated with QoL in this study, and this finding support those of studies that found that psychosocial factors affect QoL more than clinical factors such as seizure control and treatment (Suurmeijer et al., 2001).

A low QoL was present in the PWE receiving polytherapy (Gao et al., 2014; George et al., 2015; Pirio Richardson et al., 2004; Thomas et al., 2005); notably, based on literature review, side effects and polytherapy also reflect a poor QoL (Jacoby and Baker, 2008). Although monotherapy should be adapted primarily, neurologists prescribe a polytherapy when a single AED cannot control seizures (Perucca and Tomson, 2011). In parallel, combination therapy may increase the risk of side effects and drug_drug interactions, which requires monitoring of the drug level to avoid their appearance. In the presence of multiple drugs, PWE are less cooperative and may forget to take their medications. Additionally, side effects of AED were associated with poor QoL, consistent with other studies (Baker et al., 1997). Tolerance of first-line old generation AED (sodium valproate, carbamazepine, phenobarbital, phenytoin, and diazepam/clonazepam) is a major issue; many new generation AEDs have fewer side effects, and improved QoL of PWE (Lee, 2014). However, the high cost of new AEDs may be a barrier to access these molecules.

The PWE residing in northern Lebanon had a poorer QoL. The majority of Syrian refugees are concentrated in the poorest regions of Lebanon, the Bekaa and north Lebanon. In northern Lebanon, the poorest communities already had difficulties accessing basic health care services, even before the arrival of Syrian refugees (UNHCR., 2015). The dispersed settlements of the

refugee population across Lebanon had serious effects on existing health care services, and this also affects the QoL of Lebanese PWE.

The presence of psychiatric comorbidities (psychosis, anxiety, and depression) was associated with low QoL. The presence of comorbidities, with a complex and constraining regimen, implies polymedication, leading to a decrease in the level of QoL in PWE. In addition, depression may be due to a refractory treatment for PWE that failed to control seizures (Boylan et al., 2004; R. S. Taylor et al., 2011). A common mechanism of epilepsy and depression is present because of the abnormal activity of neurotransmitters in the central nervous system (Kanner et al., 2010).

Furthermore, controlled epilepsy, employed PWE, presence of myoclonic seizures, and residing in the south were found to be associated with a better QoL.

Seizure control was associated with better QoL (Djibuti and Shakarishvili, 2003). In different countries, uncontrolled epilepsy and high seizure frequency were associated with a worse QoL (Basu et al., 2008; Hamid et al., 2013; McLaughlin et al., 2010; Piperidou et al., 2008; R. S. Taylor et al., 2011). PWE without seizures presented a better QoL.

Employed PWE had a monthly income; this was associated with improvements in QoL. Their social integration improves their QoL because of self-confidence and the feeling of the absence of dependency.

The presence of generalised myoclonic seizures increased the level of QoL. In Russia and India, studies have demonstrated that PWE with focal localised seizures had poorer QoL than PWE with generalised seizures (Guekht et al., 2007; Shetty et al., 2011). However, patients with juvenile myoclonic epilepsy tend to have similar or better QoL than patients with other seizure types (McKnight, 2014). The patients who present myoclonic seizures had consciousness during

seizures, and this decreased the risk of injury. These patients were more likely to have a university degree and employment with normal social integration.

Living in southern Lebanon was associated with a better QoL. PWE who live in the south have a better QoL, especially after their previously occupied territories had been liberated. The past few years have been unprecedentedly calm in the south. Thus, there is an opportunity to sustainably engage the area after decades of abandonment, by attempting to increase health care services and economic development.

Due to the political instability and insecurity experienced by Lebanese people, a large proportion use psychotropic drugs to limit their anxieties (Abi Ghosn, 2007; David, 2007). The political context in Lebanon can also affect QoL. This context has been demonstrated in several Arab countries where socio-political realities have affected the population and were more accentuated for PWE who had low QoL scores in the Arab world (Al-Khateeb and Al-Khateeb, 2014). Some of the main factors that limited access to care services are wars in Lebanon, political crises, and the influx of refugees. Several studies have indicated that societies in situations of instability and exposed to armed conflict or living in post-conflict conditions, such as Lebanon, exhibit high levels of post-traumatic stress reactions and depression (Roberts et al., 2009; Silove, 2004). This situation also affects the QoL and attitudes of Lebanese PWE.

Notably, and particularly in Lebanon, in addition to psychiatric problems, uncontrolled epilepsy, side effects of AED and stigma that affect the QoL of PWE, and political and economic situations remain major factors that decrease the QoL for Lebanese PWE.

4.2. Factors associated with stigma

This study also revealed that nearly half of the patients felt stigmatised (47.8%). This percentage is higher than the results in Korea (31%) (Lee et al., 2005) and Turkey (34%) (Yeni et al., 2016) but lower the results from Estonia (51%) (Rätsepp et al., 2000), the United Kingdom (54%) (J. Taylor et al., 2011), Ecuador (66%) (Luna et al., 2017), and Benin (68.7%) (Rafael et al., 2010). In a large European study, more than half of the PWE felt stigmatised (Buck et al., 1999). In a study in the Middle East, a high rate of stigma was detected in Oman, and the lowest rate was in Jordan (Baker et al., 2005). These variations can be explained by the use of different tools and the difference in knowledge between populations.

PWE felt less stigmatised in sharing their epilepsy with those around them (Luna et al., 2017), and this is related to normal social integration. When PWE felt comfortable sharing their epilepsy with people, their feelings of anxiety and depression decreased; these people accepted the disease, were familiar with the illness, and had a good knowledge of epilepsy. In this study, the majority of PWE knew that epilepsy is a neurological disorder that can be inherited and it is not contagious. They participated in social activities, and this helps them feel comfortable. The need to know more information on epilepsy had a positive impact on the adaptation of PWE to their disease (Elliott and Shneker, 2008). PWE who attempted to hide their epilepsy often experienced increased anxiety and depression. In other countries, PWE can experience isolation from society due to misconceptions of epilepsy aetiology and the possibility of its transmission (Baker, 2002). Misconceptions about the cause of epilepsy such as it being contagious lead people to be afraid of marrying a PWE (Snape et al., 2009). The low rate of marriages to PWE, in China and Vietnam was due to the thought of an inherited origin of epilepsy and the economic

burden of the disease on the family (Jacoby et al., 2008). Notably, all religions support the need for patience with disease, and the necessity of PWE living normally with (Shehata, 2016).

Notably, the presence of comorbidities was associated with a low level of stigma in this study. PWE with comorbidities had adapted to live with their multiple diseases, take care of themselves, and had family support. The type of comorbidity can differently affect the stigma of PWE, and they are focused on another disease.

Additionally, side effects such as tiredness and sedation, result in avoiding social integration and increased stigmatisation. Due to the negative attitudes of society, PWE who experienced side effects have difficulties in education, finding a job, and having a family. Thus, stigma can reduce the ambition of PWE (Jacoby et al., 2005), and this can influences PWE to hide their disease (Shehata, 2016; Viteva, 2012).

In line with our study, a low QoL was associated with a high level of stigma (Bautista et al., 2015; Charyton et al., 2009). Other studies have demonstrated that PWE who had a poor QoL, were depressive, and experienced social isolation and restrictions felt more stigmatised (DiIorio et al., 2003; J. Taylor et al., 2011).

4.3. Strengths and limitations

This study enrolled a large sample of Lebanese PWE; thus, the power of the study is satisfactory. According to our review of the literature, this study is the first in Lebanon to evaluate the impact of clinical characteristics on QoL and stigma in PWE. A cross-sectional study cannot prove causality of low QoL and stigma. A precise diagnosis of epilepsy requires a neurologist, which is why PWE were recruited from neurologists' clinics. Thus, all of the sample received treatment; this leads to selection bias due to the absence of PWE without access to care. However, the

health system in Lebanon is characterised by the presence of specialists in its primary health care centres and not only in private clinics or hospitals. Thus, PWE were selected from many clinics located in different types of health care centres accessible by all Lebanese people, to be more representative of the community-based population. Self-reporting was the method used in this study; thus, information bias and social desirability bias may be present. However, information on the history of epilepsy, health status, and treatment was extracted from medical records. The Jacoby scale is commonly used to assess felt stigma among PWE; however, the evaluation of epilepsy-associated knowledge, attitudes, and practices among the public is a means to measure enacted stigma in further research. In addition, validated scales were translated to a local language and used in this study, after pilot testing. Psychometric evaluation of the Arabic version of these scales will be conducted in further research. Multivariate analyses were used in our study, and this can control confounding bias.

5. Conclusions

Assessment of QoL is a crucial step in epilepsy management to evaluate the outcome of AEDs and achieve better control of epilepsy. Implementation of intervention programmes is necessary to improve the QoL of PWE. Adapting a monotherapy to decrease the risk of side effects and the management of depression by specialists are necessary to improve QoL. PWE should be supported by society to improve services and reduce the isolation of these people. Awareness programmes and public education are necessary to improve knowledge and enhance socio-cultural attitudes towards epilepsy, to reduce stigma and improve a QoL. Beirut is visited by patients from all Lebanese regions, but it would be notable to assess these parameters in rural

areas. The difference in stigma and QoL between rural and urban areas, and between PWE with or without treatment are worthwhile topics for further research.

CONFLICT OF INTEREST

There is no conflict of interest.

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Table 1: Socio-demographic characteristics of PWE

Variables	**Mean ± SD**
Age	38.4 ± 15.7
Number of workers/ family	1.3 ± 1.0
	n (%)
Gender	
Male	207 (51.2)
Female	197 (48.8)
Region of residence	
Beirut	189 (46.8)
Bekaa	43 (10.6)
Mount Lebanon	104 (25.7)
South	52 (12.9)
North	7 (1.7)
Out Lebanon	9 (2.2)
Habitat	
Urban	319 (79.0)
Rural	85 (21.0)
Education level	
Illiterate	104 (25.7)
Primary	92 (22.8)
Intermediate	63 (15.6)
Secondary	56 (13.9)
University	89 (22.0)
Marital status	
Married	187 (46.3)
Single	161 (39.9)
Divorced	31 (7.7)
Widowed	25 (6.2)
Occupation	
Unemployed	240 (59.4)
Employed/ Self-employed	164 (40.6)
Medical Insurance	
Yes	242 (59.9)
No	162 (40.1)

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Table 2: History of epilepsy, health status, and medication

Variables		Mean ± SD
Age of epilepsy onset		26.5 ± 18.8
Duration of epilepsy		12.3 ± 12.1
Number of comorbidities		1.1 ± 1.4
		n (%)
Presence of comorbidities		
	Yes	220 (54.5)
	No	184 (45.5)
Type of comorbidities		
	Psychiatric	122 (30.2)
	Cardiovascular	99 (24.5)
	Endocrine	52 (12.9)
	Gastrointestinal	28 (6.9)
	Respiratory	16 (4.0)
Controlled epilepsy		
	Yes	187 (46.3)
	No	217 (53.7)
Active epilepsy		
	Yes	329 (81.4)
	No	75 (18.6)
Seizure type		
	Simple partial/focal	66 (16.3)
	Complex partial/focal	145 (35.9)
	Secondary generalised	48 (11.9)
	Generalised tonic clonic	124 (30.7)
	Generalised myoclonic	24 (5.9)
	Generalised atonic	3 (0.7)
	Absence	33 (8.2)
	Others	1 (0.2)
Epilepsy aetiology		
	Cryptogenic/unknown + Idiopathic/genetic	190 (47)
	Symptomatic/structural-metabolic	214 (53)
Experiencing of side effects		
	Yes	206 (51.0)
	No	198 (49.0)
Antiepileptic Therapy		
	Monotherapy	233 (57.7)
	Polytherapy	171 (42.3)
Medication adherence		
	Adherent	141 (34.9)
	Nonadherent	263 (65.1)
Cause of epilepsy		
Neurological disorder that can be inherited		219 (54.2)
	Mental	70 (17.3)
	Only hereditary	27 (6.7)
	Don’t know	88 (21.8)
Epilepsy is contagious		
	Yes	19 (4.7)
	No	298 (73.8)
	Don’t know	87 (21.5)

Table 3: Distribution of Jacoby scale's answers and association with the stigma

		n (%)	Stigmatised	Nonstigmatised	p_value
1.Uncomfortable with PWE					
	Yes	184 (45.5)	184 (95.3)	0 (0)	
	No	220 (54.5)	9 (4.7)	211 (100)	<0.001
2. Treat PWE as inferior					
	Yes	118 (29.2)	118 (61.1)	0 (0)	
	No	286 (70.8)	75 (38.9)	211 (100)	<0.001
3. Prefer to avoid PWE					
	Yes	159 (39.4)	159 (82.4)	0 (0)	
	No	245 (60.6)	34 (17.6)	211 (100)	<0.001

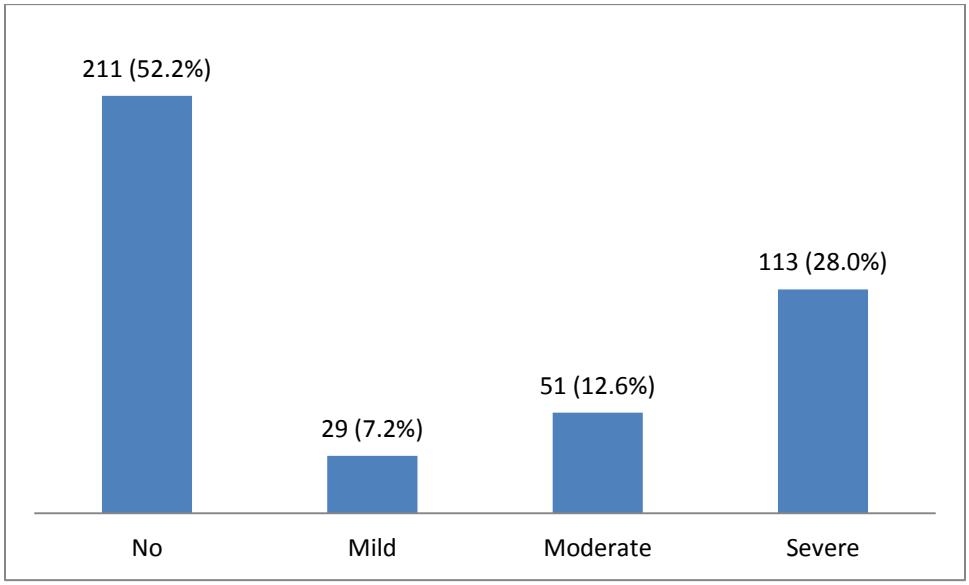


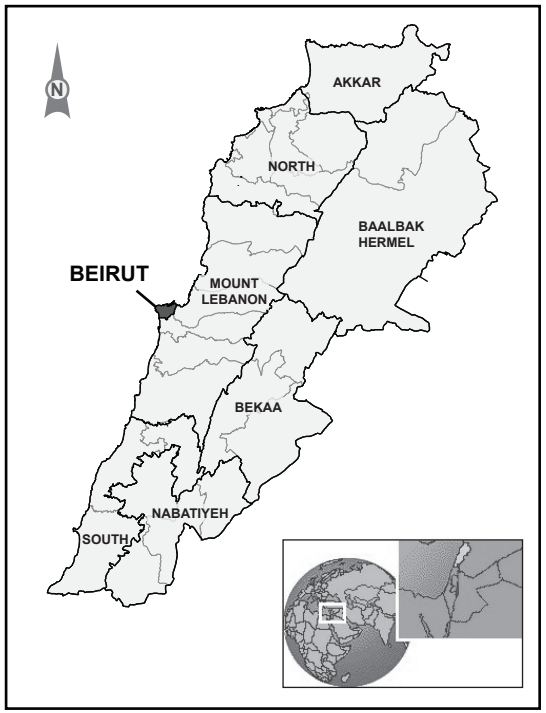
Fig.2. Distribution of the stigma levels

Table 4: Factors associated with the Quality of Life of PWE

Variables		Univariate analysis		Multivariate analysis			
		QoL	p_value	Unstandardised coefficients		Standardised coefficients	p_value
		Mean ± SD		Beta	SD		
Gender							
	Male	27.8 ± 11.9	0.1				
	Female	25.9 ± 10.6		-1.64	0.99	-0.07	0.09
Region of residence							
	Beirut	27.3 ± 10.7					
	Bekaa	27.2 ± 12.9					
	Mount Lebanon	26.3 ± 11.3	0.1				
	South	25.7 ± 11.1		-2.85	1.46	-0.09	0.05
	North	37.7 ± 4.2		11.16	3.66	0.13	0.003
	Out Lebanon	23.3 ± 17.4					
Education level							
	Illiterate	29.1 ± 11.4					
	Primary	29.6 ± 11.9	0.001				
	Intermediate	25.3 ± 10.6					
	Secondary	24.6 ± 10.6					
	University	26.9 ± 11.3					
Marital status							
	Married	26.0 ± 10.8					
	Single	27.8 ± 11.7	0.5				
	Divorced	27.8 ± 13.1					
	Widowed	26.7 ± 9.8					
Occupation							
	Unemployed	28.3 ± 11.6	0.002				
	Employed/ Self-employed	24.8 ± 10.5		-3.47	0.99	-0.15	0.001
Medical Insurance							
	Yes	26.4 ± 11.1	0.3				
	No	27.7 ± 11.6					
Presence of psychiatric comorbidities							
	Yes	29.0 ± 11.1	0.01	2.25	1.06	0.09	0.03
	No	26.0 ± 11.3					
Controlled epilepsy							
	Yes	25.1 ± 10.7	0.003	-2.24	0.97	-0.09	0.02
	No	28.4 ± 11.6					
Seizures in the last 5 years							
	Yes	27.3 ± 11.4	0.2				
	No	25.3 ± 10.7					
Experiencing side effects							
	Yes	28.9 ± 10.6	<0.001	3.12	0.96	0.14	0.001
	No	24.8 ± 11.6					
Antiepileptic Therapy (Number of AED/day)							
	Monotherapy	25.1 ± 10.9	<0.001				
	Polytherapy	29.3 ± 11.4		3.01	0.99	0.13	0.002
Stigmatised							
	Yes	31.8 ± 11.5	<0.001	8.38	0.97	0.37	<0.001
	No	22.4 ± 9.1					
Medication adherence							
	Adherent	23.7 ± 10.4	<0.001				
	Nonadherent	28.6 ± 11.4					
Generalised myoclonic seizure	Yes	21.1 ± 9.2	0.009	-5.17	2.04	-0.11	0.01
	No	27.3 ± 11.3					
Secondary generalised seizure	Yes	30.5 ± 12.0	0.02				
	No	26.4 ± 11.1					
Epilepsy aetiology							
Cryptogenic/unknown + Idiopathic/genetic		25.9 ± 10.9	0.09				
Symptomatic/structural-metabolic		27.8 ± 11.5					
		Pearson Correlation	**p-value**				
Age		0.1	0.04	0.09	0.03	0.12	0.004
Number of workers/ family		-0.08	0.1				

Table 5: Factors associated with the Stigma of PWE

Variables		Univariate analysis			Multivariate analysis		
		Stigmatised n (%)	**Nonstigmatised n (%)**	**p_value**	**OR**	**CI**	**p_value**
Gender							
	Male	104 (53.9)	103 (48.8)	0.3			
	Female	89 (46.1)	108 (51.2)				
Habitat							
	Urban	155 (80.3)	164 (77.7)	0.5			
	Rural	38 (19.7)	47 (22.3)				
Education level							
	Illiterate	54 (28.0)	50 (23.7)	0.2			
	Primary	50 (25.9)	42 (19.9)				
	Intermediate	29 (15.0)	34 (16.1)				
	Secondary	20 (10.4)	36 (17.1)				
	University	40 (20.7)	49 (23.2)				
Marital status							
	Married	80 (41.5)	107 (50.7)	0.07			
	Single	85 (44.0)	76 (36)				
	Divorced	19 (9.8)	12 (5.7)				
	Widowed	9 (4.7)	16 (7.6)				
Occupation							
	Unemployed	123 (63.7)	117 (55.5)	0.09			
	Employed/ Self-employed	70 (36.3)	94 (44.5)				
Medical Insurance							
	Yes	118 (61.1)	124 (58.8)	0.6			
	No	75 (38.9)	87 (41.2)				
Presence of comorbidities							
	Yes	98 (50.8)	122 (57.8)	0.16	0.4	0.2-0.9	0.02
	No	95 (49.2)	89 (42.2)				
Controlled epilepsy							
	Yes	81 (42.0)	106 (50.2)	0.1			
	No	112 (58.0)	105 (49.8)				
Seizures in the last 5 years							
	Yes	165 (85.5)	164 (77.7)	0.045			
	No	28 (14.5)	47 (22.3)				
Experiencing side effects							
	Yes	111 (57.5)	95 (45.0)	0.01	2.02	1.02-4.01	0.045
	No	82 (42.5)	116 (55.0)				
Antiepileptic Therapy (Number of AED/day)							
	Monotherapy	105 (54.4)	128 (60.7)	0.2			
	Polytherapy	88 (45.6)	83 (39.3)				
Medication adherence							
	Adherent	45 (23.3)	96 (45.5)	<0.001			
	Nonadherent	148 (76.7)	115 (54.5)				
Cause of epilepsy							
	Nervous	83 (43.0)	136 (64.5)	<0.001			
	Mental	41 (21.2)	29 (13.7)				
	Hereditary	14 (7.3)	13 (6.2)				
	Don't know	55 (28.5)	33 (15.6)				
Epilepsy is contagious							
	Yes	10 (5.2)	9 (4.3)	0.1			
	No	133 (68.9)	165 (78.2)				
	Don't know	50 (25.9)	37 (17.5)				
Epilepsy can be treated							
	Yes	46 (23.8)	93 (44.1)	<0.001			
	No	81 (42.0)	66 (31.3)				
	Don't know	66 (34.2)	52 (24.6)				
PWE receive advice							
	Yes	153 (79.3)	173 (82.0)	0.5			
	No	40 (20.7)	38 (18.0)				
PWE can participate in social activities							
	Yes	94 (48.7)	179 (84.8)	<0.001	0.5	0.2-1.1	0.08
	No	99 (51.3)	32 (15.2)				
PWE share their epilepsy with those around them							
	Yes	34 (17.6)	149 (70.6)	<0.001	0.07	0.03-0.15	<0.001
	No	159 (82.4)	62 (29.4)				
		Mean ± SD		**p_value**			
Age		37.1 ± 14.2	39.7±17.0	0.09			
Duration of epilepsy		12.6 ± 11.8	11.9±12.3	0.6			
Age of epilepsy onset		24.4 ± 16.5	27.7 ± 20.3	0.07			
QOLIE-10 Score		31.8 ± 11.5	22.4 ± 9.1	<0.001	1.05	1.02-1.09	0.005


N
AKKAR
NORTH
BAALBAK
HERMEL
BEIRUT
MOUNT
LEBANON
BEKAA
NABATIYEH
SOUTH