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

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31 **Abstract**

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

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

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

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

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

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## 61        **1. Introduction**

62        Epilepsy is a neurological disorder that affects more than 70 million people worldwide, of whom  
63        80% reside in developing countries (Ngugi et al., 2010). This disorder is one of the most  
64        important public health problems, which affects people with epilepsy (PWE), their families, and  
65        society (Boling et al., 2018). This disease is characterised by unpredictable symptoms, such as a  
66        loss of consciousness, and is associated with considerable psychological consequences (Hermann  
67        and Jacoby, 2009), which can prevent PWE from driving, getting married, or employment,  
68        because of the risk of seizure (Boer et al., 2008). These consequences negatively affect the  
69        quality of life (QoL) of PWE (Jacoby et al., 2005) and can lead to their stigmatisation (Loring et  
70        al., 2004). Improving QoL is one of the goals of epilepsy management (Perucca and Tomson,  
71        2011; Privitera and Ficker, 2004). Assessment of QoL is a means to identify the severity of  
72        seizures (Vickrey et al., 2000) and evaluate the effect of anti-epileptic drugs (AED; Birbeck et  
73        al., 2007; Gilliam et al., 2004; Melikyan et al., 2012).

74        Studies have demonstrated that QoL is lower among PWE compared to the general population  
75        (Villeneuve, 2004). In Europe and North America, PWE had a poor QoL (Buck et al., 1999;  
76        Stavem et al., 2000). Despite the data indicating a high prevalence of PWE in Africa (Meinardi  
77        et al., 2001), few studies have been published on the QoL in these populations (Mrabet et al.,  
78        2004). In the Arab world, a low QoL score has been detected in most studies (Al-Khateeb and  
79        Al-Khateeb, 2014). Socio-demographic and clinical factors affect the QoL of PWE and increase  
80        the stigma (Baker et al., 1997; Sanyal and Roy, 2004).

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

84 because of their perceived inferiority (Jacoby, 1994). Felt stigma is the self-stigmatisation of  
85 PWE related to shame and fear of discrimination (Jacoby, 2008, 1994). Many studies have  
86 indicated that 50% to 70% of PWE feel stigmatised (Lee et al., 2016; Luna et al., 2017; Sleeth et  
87 al., 2016). Social stigma of PWE has occurred in developed and developing regions (Baker et al.,  
88 2005; Guekht et al., 2007). Insufficient information about epilepsy leads to stigma (Zanni et al.,  
89 2012), contributes to hiding the disease, and decreases medication adherence (Inzlicht et al.,  
90 2006). The perceptions and knowledge of PWE regarding their disease play an additional role in  
91 the evaluation of the consequences of epilepsy on their daily functions (Cramer et al., 1996).  
92 Psychiatric comorbidities, including anxiety and depression, are more frequent in PWE who felt  
93 stigmatised (Leaffer et al., 2014; Wang et al., 2015). The factors contributing to a stigma vary by  
94 country and culture, for example, seizure severity, social support, QoL, and depression (Benson  
95 et al., 2016; Leaffer et al., 2014; Smith et al., 2009).

96 In the Arab region, stigma is among the main psychosocial problems of PWE, who have low  
97 overall QoL scores (Al-Khateeb and Al-Khateeb, 2014). In a study of 10 Middle East regions in  
98 2005, including Lebanon, QoL was evaluated by using 36-Item short-form survey (SF-36)  
99 (Baker et al., 2005); however, data on the level of QoL and factors affecting this QoL of  
100 Lebanese PWE were absent. Information regarding QoL and stigma in Lebanese PWE is limited.  
101 Due to this knowledge gap, this study's primary and secondary aims are to evaluate QoL and  
102 stigma in Lebanese PWE and identify the factors affecting these parameters, respectively.

103

## 104 **2. Materials and method**

### 105 **2.1. Study design**

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

110

## 111 **2.2. Study population**

112 The estimated minimal sample size was 384 patients, using 95% as the confidence interval (CI),  
113 5% for precision error (Charan and Biswas, 2013), and 50% as the estimated percentage of PWE  
114 who were having a better QoL and not stigmatised, because of a lack of data in the literature.

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

121

## 122 **2.3. Data collection**

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

125 The questionnaire had six parts:

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

128 - History of epilepsy: duration of disease, age of epilepsy onset, presence of active epilepsy  
129 (defined by the presence of seizures in the last 5 years), controlled epilepsy (no seizure in the last  
130 6 months) (Ferrari et al., 2013; Smithson et al., 2013)), seizure type (simple partial/focal,  
131 complex partial/focal, tonic clonic, myoclonic, atonic, absence), epilepsy aetiology  
132 (symptomatic/structural-metabolic, idiopathic/genetic, cryptogenic/unknown) (Fisher et al.,  
133 2017; Scheffer et al., 2017).

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

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

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

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

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

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

149

#### 150 **2.4. Measuring instruments and assessment criteria**

151        **2.4.1. Medication adherence scale**

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

159        **2.4.2. QoL scale**

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

172        **2.4.3. Stigma scale**

173 Jacoby's stigma scale was a validated scale to assess felt stigma among PWE (Jacoby et al.,  
174 1996) and comprises three questions: *Are people without epilepsy uncomfortable with PWE? Do*  
175 *people without epilepsy treat PWE as inferior? and Do people without epilepsy prefer to avoid*  
176 *PWE?* A 'Yes' response was coded 1, and a 'No' response was coded 0. The score ranged from 0  
177 to 3. Four categories were established: no stigma (score =0), mild (score=1), moderate (score=2),  
178 and severe (score=3). The Jacoby scale has been validated and used with PWE in Lebanon,  
179 namely, one study of 10 middle eastern countries (Baker et al., 2005).

180

## 181 **2.5. Translation of questionnaires, scales, and forms**

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

191

## 192 **2.6. Statistical analysis**

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

196 translated Arabic scale. A value of Cronbach's alpha was greater than 0.5 for the three scales  
197 (0.73 for MMAS-4; 0.55 for QOLIE-10; 0.89 for Jacoby scale); this finding showed that the  
198 questionnaire was considered reliable.

199 Student t\_test and one-way ANOVA were used to compare means. The chi\_square and Fisher's  
200 exact test were used to compare percentages between groups. The results of univariate analysis  
201 indicated that the variables with a p\_value of <0.2 should be selected for multivariable analysis.  
202 A backward linear regression was built to determine factors associated with QoL, using 'total  
203 QOLIE-10 score' as a dependent variable. A backward logistic regression was conducted to  
204 identify factors associated with stigma by using 'stigmatised: yes/no' as a dependent variable.  
205 The statistical significance of the results was determined according to 95% confidence intervals.  
206 A p\_value of  $\leq 0.05$  was considered statistically significant throughout the study.

207

### 208 **3. Results**

#### 209 **3.1. Socio-demographic characteristics**

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

212

#### 213 **3.2. History of epilepsy and health status**

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

218

219 **3.3. Antiepileptic medication and compliance**

220 Sodium valproate was the most common AED prescribed in monotherapy and polytherapy  
221 (49.0%). More than one AED per day was prescribed for 42.3% of PWE. Side effects due to  
222 AED we observed in 51.0% of PWE (Table 2). Tiredness and drowsiness were the main side  
223 effects experienced by PWE. Among the 404 PWE, 141 (34.9%) were adherent to treatment  
224 (Table 2).

225

226 **3.4. Levels of stigma in PWE**

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

232

233 **3.5. QoL and factors associated**

234 The mean QOLIE-10 score was  $26.9 \pm 11.3$ , ranging from 10 to 51. The majority of PWE  
235 (61.4%) had a high QoL (score  $< 30.5$ ); however, almost one third had a low QoL (score  $> 30.5$ ).  
236 The linear regression showed that PWE who worked (Beta = -3.47,  $p=0.001$ ), who lived in the  
237 south (Beta = -2.85,  $p=0.05$ ), and who had controlled epilepsy (Beta = -2.24,  $p=0.02$ ) were  
238 associated with a low QOLIE-10 score (i.e. a better QoL; Table 4).

239 However, a stigma and living in the north significantly increased the QOLIE-10 score (Beta =  
240 8.38,  $p<0.001$  and Beta = 11.16,  $p=0.003$ ). Furthermore, presence of psychiatric comorbidities  
241 (Beta = 2.25,  $p=0.03$ ), experiencing side effects (Beta = 3.12,  $p=0.001$ ), polytherapy (Beta =

242 3.01,  $p=0.002$ ), and older 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

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

267 Based on an assessment of the QoL of PWE in 10 Middle East regions and using another scale  
268 (SF-36), Oman presented the lowest overall score; however, Bahrain, Lebanon, and Qatar  
269 presented the highest score for the main domains of SF-36 (Baker et al., 2005). In addition, an  
270 overview of studies on the QoL of PWE in Arab countries showed that the SF-36 was used in  
271 studies in Arab countries to compare the QoL of PWE and the general population as a control  
272 group (Al-Khateeb and Al-Khateeb, 2014). The results of studies conducted in nine out of the 22  
273 Arab countries showed that the QoL of PWE was generally low (Al-Khateeb and Al-Khateeb,  
274 2014). This scale is not specifically for epilepsy and can be used for the general population. A  
275 comparison of the results of the studies that have used other instruments to evaluate QoL was  
276 difficult.

277 More specifically, in Lebanon, the QoL in PWE was evaluated in specific circumstances (after  
278 surgery, after vagal nerve stimulator insertion, and after temporal lobectomy) (Mikati et al.,  
279 2010, 2009, 2008, 2006, 2004). However, in our study, QOLIE-10 was used as a specific  
280 instrument for epilepsy to evaluate QoL in Lebanese PWE in clinical settings.

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

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

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

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

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

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

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

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

318  
319 Furthermore, controlled epilepsy, employed PWE, presence of myoclonic seizures, and residing  
320 in the south were found to be associated with a better QoL.

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

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

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

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

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

340  
341 Due to the political instability and insecurity experienced by Lebanese people, a large proportion  
342 use psychotropic drugs to limit their anxieties (Abi Ghosn, 2007; David, 2007). The political  
343 context in Lebanon can also affect QoL. This context has been demonstrated in several Arab  
344 countries where socio-political realities have affected the population and were more accentuated  
345 for PWE who had low QoL scores in the Arab world (Al-Khateeb and Al-Khateeb, 2014). Some  
346 of the main factors that limited access to care services are wars in Lebanon, political crises, and  
347 the influx of refugees. Several studies have indicated that societies in situations of instability and  
348 exposed to armed conflict or living in post-conflict conditions, such as Lebanon, exhibit high  
349 levels of post-traumatic stress reactions and depression (Roberts et al., 2009; Silove, 2004). This  
350 situation also affects the QoL and attitudes of Lebanese PWE.

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

354

#### 355 **4.2. Factors associated with stigma**

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

364  
365 PWE felt less stigmatised in sharing their epilepsy with those around them (Luna et al., 2017),  
366 and this is related to normal social integration. When PWE felt comfortable sharing their  
367 epilepsy with people, their feelings of anxiety and depression decreased; these people accepted  
368 the disease, were familiar with the illness, and had a good knowledge of epilepsy. In this study,  
369 the majority of PWE knew that epilepsy is a neurological disorder that can be inherited and it is  
370 not contagious. They participated in social activities, and this helps them feel comfortable. The  
371 need to know more information on epilepsy had a positive impact on the adaptation of PWE to  
372 their disease (Elliott and Shneker, 2008). PWE who attempted to hide their epilepsy often  
373 experienced increased anxiety and depression. In other countries, PWE can experience isolation  
374 from society due to misconceptions of epilepsy aetiology and the possibility of its transmission  
375 (Baker, 2002). Misconceptions about the cause of epilepsy such as it being contagious lead  
376 people to be afraid of marrying a PWE (Snape et al., 2009). The low rate of marriages to PWE,  
377 in China and Vietnam was due to the thought of an inherited origin of epilepsy and the economic

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

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

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

389 In line with our study, a low QoL was associated with a high level of stigma (Bautista et al.,  
390 2015; Charyton et al., 2009). Other studies have demonstrated that PWE who had a poor QoL,  
391 were depressive, and experienced social isolation and restrictions felt more stigmatised (DiIorio  
392 et al., 2003; J. Taylor et al., 2011).

393

#### 394 **4.3. Strengths and limitations**

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

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

413

## 414 **5. Conclusions**

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

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

425

426 **CONFLICT OF INTEREST**

427 There is no conflict of interest.

428

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432

433

434

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<b>Table 1: Socio-demographic characteristics of PWE</b>		709
<b>Variables</b>		<b>Mean ± SD</b>
<b>Age</b>		38.4 ± 7.507
<b>Number of workers/ family</b>		1.3 ± 1.0
		<b>n(%)</b>
<b>Gender</b>		
	Male	207 (51.2)
	Female	197 (48.8)
<b>Region of residence</b>		713
	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)
<b>Habitat</b>		716
	Urban	319 (79.0)
	Rural	85 (21.0)
<b>Education level</b>		
	Illiterate	104 (25.7)
	Primary	92 (22.8)
	Intermediate	63 (15.6)
	Secondary	56 (13.9)
	University	89 (22.0)
<b>Marital status</b>		
	Married	187 (46.3)
	Single	161 (39.9)
	Divorced	31 (7.7)
	Widowed	25 (6.2)
<b>Occupation</b>		
	Unemployed	240 (59.4)
	Employed/ Self-employed	164 (40.6)
<b>Medical Insurance</b>		
	Yes	242 (59.9)
	No	162 (40.1)

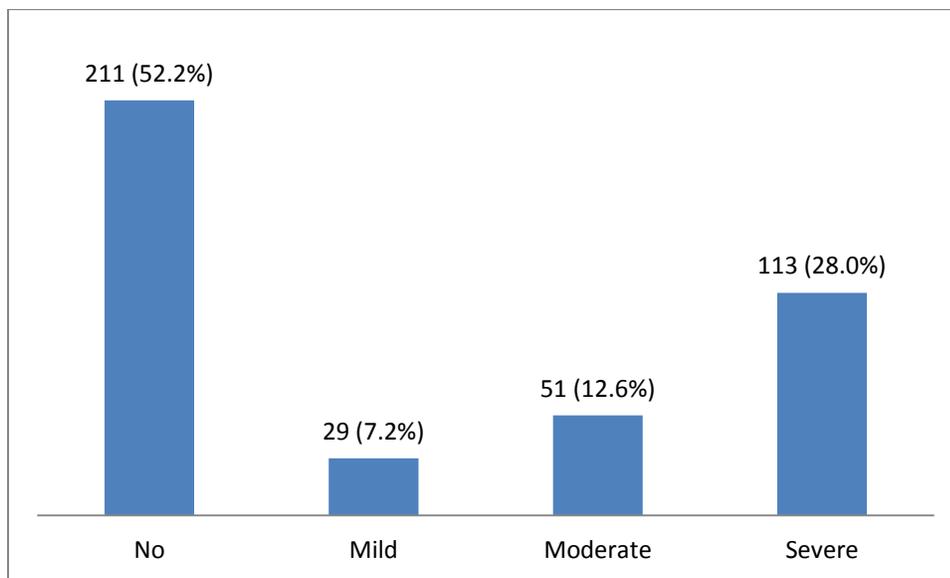
**Table 2: History of epilepsy, health status, and medication**

<b>Variables</b>	<b>Mean ± SD</b>
<b>Age of epilepsy onset</b>	26.5 ± 18.8
<b>Duration of epilepsy</b>	12.3 ± 12.1
<b>Number of comorbidities</b>	1.1 ± 1.4
	<b>n (%)</b>
<b>Presence of comorbidities</b>	
Yes	220 (54.5)
No	184 (45.5)
<b>Type of comorbidities</b>	
Psychiatric	122 (30.2)
Cardiovascular	99 (24.5)
Endocrine	52 (12.9)
Gastrointestinal	28 (6.9)
Respiratory	16 (4.0)
<b>Controlled epilepsy</b>	
Yes	187 (46.3)
No	217 (53.7)
<b>Active epilepsy</b>	
Yes	329 (81.4)
No	75 (18.6)
<b>Seizure type</b>	
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)
<b>Epilepsy aetiology</b>	
Cryptogenic/unknown + Idiopathic/genetic	190 (47)
Symptomatic/structural-metabolic	214 (53)
<b>Experiencing of side effects</b>	
Yes	206 (51.0)
No	198 (49.0)
<b>Antiepileptic Therapy</b>	
Monotherapy	233 (57.7)
Polytherapy	171 (42.3)
<b>Medication adherence</b>	
Adherent	141 (34.9)
Nonadherent	263 (65.1)
<b>Cause of epilepsy</b>	
Neurological disorder that can be inherited	219 (54.2)
Mental	70 (17.3)
Only hereditary	27 (6.7)
Don't know	88 (21.8)
<b>Epilepsy is contagious</b>	
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
<b>1.Uncomfortable with PWE</b>				
Yes	184 (45.5)	184 (95.3)	0 (0)	<0.001
No	220 (54.5)	9 (4.7)	211 (100)	
<b>2. Treat PWE as inferior</b>				
Yes	118 (29.2)	118 (61.1)	0 (0)	<0.001
No	286 (70.8)	75 (38.9)	211 (100)	
<b>3. Prefer to avoid PWE</b>				
Yes	159 (39.4)	159 (82.4)	0 (0)	<0.001
No	245 (60.6)	34 (17.6)	211 (100)	

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**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				
	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
	North	37.7 ± 4.2		11.16	3.66	0.13
	Out Lebanon	23.3 ± 17.4				0.003
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
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
	No	26.0 ± 11.3				0.03
Controlled epilepsy						
	Yes	25.1 ± 10.7	0.003	-2.24	0.97	-0.09
	No	28.4 ± 11.6				0.02
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
	No	24.8 ± 11.6				0.001
Antiepileptic Therapy (Number of AED/day)						
	Monotherapy	25.1 ± 10.9	<0.001			
	Polytherapy	29.3 ± 11.4		3.01	0.99	0.13
Stigmatised						
	Yes	31.8 ± 11.5	<0.001	8.38	0.97	0.37
	No	22.4 ± 9.1				<0.001
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
	No	27.3 ± 11.3				0.01
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				
			<b>Pearson Correlation</b>	<b>p-value</b>		
Age		0.1	0.04	0.09	0.03	0.12
Number of workers/ family		-0.08	0.1			0.004

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

