



A comparative study of health related quality of life, psychological well-being, impact of illness and stigma in epilepsy and migraine

Nuran Aydemir^{a,*}, Çiğdem Özkara^b, Pınar Ünsal^c, Reşit Canbeyli^d

^a Izmir University of Economics, Faculty of Art and Sciences, Department of Psychology, Sakarya Cad. No: 156, 35330 Balçova, Izmir, Turkey

^b Istanbul University, Cerrahpaşa School of Medicine, Department of Neurology, Istanbul, Turkey

^c Istanbul University, Faculty of Letters, Department of Psychology, Istanbul, Turkey

^d Boğaziçi University, Faculty of Art and Sciences, Department of Psychology, Istanbul, Turkey

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ABSTRACT

This study aimed to show the difference of epilepsy from another chronic neurological disorder with episodic manifestations (CDEM): migraine. Seventy persons with epilepsy (PWE), 56 persons with migraine (PWM) and 45 healthy control participants (HCs) were included. The groups were compared in terms of demographics, quality of life, depression and self-esteem. The PWE and PWM were also compared with regard to stigma, impact of the illness, disclosure, application of spiritual/traditional healing methods, limitations, most affected life areas, and restrictions. Results showed that the PWM had lower quality of life values than the PWE and the HCs, while there was no difference among the groups in depression and self-esteem. Results also show higher unemployment levels and lower marriage rates for the PWE, where education levels were equal. Although the PWM had higher impact of illness values, the PWE were shown to have higher stigma, more concealment behavior, and higher traditional/spiritual healing application ratios. Also, the PWM emphasized the importance of being “able to fulfil daily living, social and work activities”, while the PWE emphasized the need for “independence” constantly. These results indicate that, although both migraine and epilepsy are CDEMs, they have different levels of impact on patients' lives. The impacts are socially greater in epilepsy and extend beyond the neurological condition itself.

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1. Introduction

Epilepsy is a common chronic neurological disorder which is characterized by recurrent seizures. However, classifying epilepsy merely as a neurological disorder is inadequate since it is also a disorder with negative social consequences. Persons with epilepsy (PWE) usually suffer from unemployment and/or underemployment, lower marriage rates, and social discrimination.^{1–4} All these factors usually result in an impaired quality of life and low self-esteem, which is intensified by the seizures themselves,^{5,6} and sometimes even by antiepileptic drug (AED) use.^{7–9} For most PWE, a diagnosis of epilepsy is equal to stigmatization,^{10,11} in particular felt stigma,¹² which in turn results in concealing epilepsy from others and spending a great amount of energy on this concealment.^{13–15} This situation also creates a serious psychological burden and sometimes social restrictions in their lives. Additionally, many PWE suffer from depression, which also impairs quality of life and introduces additional problems.^{6,16–18} Moreover, a range

of mythological and superstitious beliefs seem to surround epilepsy in every culture,^{19,20} creating a body of unscientific and misguided attitudes. This in turn, leads to the practice of traditional and spiritual healing methods, which can be observed across a wide spectrum of cultures.^{13,21–23}

Migraine is another very common neurological disorder which is characterized by recurrent attacks of pain and associated symptoms.²⁴ Both epilepsy and migraine are neurological chronic disorders with episodic manifestations (CDEMs).²⁵ Although the duration of the symptoms varies greatly in these two disorders, individuals with either condition may have symptom free periods between attacks/seizures. In both illnesses, neurological attacks can be accompanied by headache as well as by variant gastrointestinal, autonomic and psychological features.²⁶ It is believed that both result from brain hyperexcitability.²⁷ Both are umbrella disorders, each of which constitutes a heterogeneous family of disorders. In some cases, common drugs – such as, valproic acid and topiramate – are used in the treatment of both.^{28,29} Additionally, like epilepsy, migraine can cause impaired quality of life,^{30–33} and generally has a negative impact on life.³⁴ Mood disorders, especially anxiety and depression, are also common comorbid conditions in migraine and epilepsy.^{30,35}

* Corresponding author. Tel.: +90 232 488 85 25; fax: +90 232 279 26 26.

E-mail address: nuran.aydemir@ieu.edu.tr (N. Aydemir).

Despite these similarities, however, migraine and epilepsy constitute different disorders. There are a number of previous studies in which epilepsy is compared with other chronic illnesses, such as angina pectoris, rheumatoid arthritis, asthma, chronic obstructive pulmonary disease, migraine, atopic dermatitis, cerebral palsy, and cystic fibrosis.^{36–39} However, the aim of using migraine as a second research group is to highlight the contrasts between epilepsy and another illness with very similar features. The reason for this is that observed differences in quality of life between PWE and people with other chronic illnesses with very different symptoms could be attributed to the completely different etiologies and symptoms of the disorders. By using migraine therefore, it is aimed to examine possible differences between epilepsy and a similar illness in order to eliminate confounding nature of the symptoms and etiologies. Hence, any difference observed could be directly attributed to the specific nature of epilepsy.

Therefore, the present study aimed to compare PWE and persons with migraine (PWM) in terms of health related quality of life, self-esteem, impact of illness, depression, stigma and disclosure. Other affected life domains and application of spiritual/traditional healing methods were also investigated in order to understand more about what makes epilepsy different. Based on previous studies, we expected: (1) lower health related quality of life (HRQOL) values in PWM and PWE than Control participants (CPs), and in particular that PWM would have lower HRQOL values on the subscales related with physical health, and PWE have lower values on the subscales related with mental health; (2) higher depression and stigma rates and lower self-esteem values in PWE; (3) higher impact of illness scores in PWM; (4) more application of traditional/spiritual healing methods in PWE; and (5) more concealment of the illness in PWE.

2. Methods

2.1. Participants

The epilepsy group consisted of seventy participants diagnosed with epilepsy at least for four years previously, and who experienced at least one seizure within the last two years and/or who are still on AEDs. All participants in the epilepsy group had detailed neurological and neuropsychological evaluations, and patients with below average IQs (less than 90) were not included in the study. Patients with additional serious impairments (e.g. hearing, seeing, etc.) and those with other neurological and psychiatric disorders were also excluded.

For the migraine group, 56 adults with migraine were recruited. The selection criteria were experiencing migraine attacks for an absolute minimum of four years, including at least one attack in the last three months, and continuing treatment at a headache polyclinic and as well as being on prescribed medication. Likewise, PWM with below average IQs (less than 90), with additional serious impairments, and those with other neurological and psychiatric disorders were also excluded. Since epilepsy and migraine are highly comorbid, patients who have migraine or epilepsy as a comorbid condition were excluded from the study. All the participants with migraine and epilepsy were recruited during their follow-up appointments in the neurology clinic.

A control group, consisting 45 healthy adults with no history of neurological and psychiatric disorders was included. The control participants (CPs) were matched with the epilepsy and migraine groups in terms of age, gender, and year of education as far as possible (see Table 1).

The present study was approved by the Cerrahpaşa School of Medicine, and Faculty of Ethics Committee [31.01.2006, No: 2378] at Istanbul University. Additionally, all the participants gave informed consent for their participation in the study.

Table 1

Demographic characteristics of epilepsy, migraine and control groups.

Groups	Epilepsy (n=70)	Migraine (n=56)	Healthy control (n=46)
Sex (%) *			
Female	68.6	87.5	60.9
Age (SD) *	32.3 (10.5)	40.5 (10.4)	35.7 (11)
Year of education (SD)	9.2 (3.9)	9.0 (4.4)	9.3 (4.4)
Marital status (%) *			
Single	48.6	12.5	15.2
Married	42.9	82.1	73.9
Divorced	2.9	–	6.5
Widow	5.7	5.4	4.3
Occupational status (%) *			
Employed	47.1	33.9	71.7
Unemployed	14.3	5.4	2.2
Housewife	22.9	41.1	19.6
Student	14.3	5.4	4.3
Retired	1.4	4.3	2.2

* $p < 0.00$.

2.2. Instruments

2.2.1. Health related quality of life (HRQOL)

We used the Medical Outcomes study short form-36 (SF-36),⁴⁰ which consists of eight subscales to evaluate different domains of HRQOL: (1) physical functioning (PF); (2) role limitations because of physical health problems (RP); (3) bodily pain (BP); (4) social functioning (SF); (5) general mental health (psychological distress and psychological well being) (MH); (6) role limitations because of emotional problems (RE); (7) vitality (energy/fatigue) (VT); and (8) general health perception (GH). The total score varies between 0 and 100, with higher scores representing a better quality of life. Although it is a generic measure, SF-36 has been used in previous quality of life research in epilepsy.^{7,39,41–50} The validity and reliability of SF-36 for Turkish population have been tested by Demirsoy.⁵¹

2.2.2. Depression

The Beck Depression Inventory (BDI),⁵² a 21 item scale, was administered to assess the depression levels of the participants. The total score varies between 0 and 63, with higher scores indicating the severity of the depressive symptoms. In the present study, 17 was accepted as a cut off point for severe depression. The validity and reliability of the BDI for the Turkish population have been tested by Hıslı.⁵³

2.2.3. Stigma

A three item scale developed by Jacoby⁵⁴ was used. In this scale, subjects are asked to state whether, because of their epilepsy, they felt that other people are (1) uncomfortable with them, (2) treated them as inferior, and (3) preferred to avoid them. The subjects marked each item with which they agreed. The subject's overall score (0–30) is the sum of positive responses, therefore the higher the score, the greater sense of stigma. The reliability of the scale was found to be 0.72.⁵⁴

2.2.4. Impact of illness

The Perceived Impact of Epilepsy Scale, developed by Jacoby et al.⁵⁵ was administered to determine the impact of epilepsy on daily life. The scale contains both generic and epilepsy-specific items. All items cover the most important areas of everyday life, including relationships with spouse/partners, relationships with other close family members, social life/social activities, work, health, relationships with friends, feelings about self, and plans and ambitions for the future. When the scale was administered to patients with migraine, the term “migraine” replaced “epilepsy” in

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