Neurological Sciences
https://doi.org/10.1007/s10072-022-05888-1

ORIGINAL ARTICLE

An invisible cause of disability: stigma in migraine and epilepsy

Fulya Basoglu Koseahmet[1] · Burcu Polat[2] · R. Gokcen Gozubatik-Celik[3] · Isil Baytekin[3] · Muazzez Gokcen Soylu[3] · Ayten Ceyhan Dirican[3] · Musa Ozturk[3]

Received: 31 October 2021 / Accepted: 10 January 2022

Abstract

Objective Our purpose was to identify the ratio and severity of stigmatization in patients with migraine and epilepsy. We also collected demographic and clinical data to search for possible facilitators.

Methods In total, 196 patients with migraine and 60 patients with epilepsy were enrolled. Neuro-QoL Stigma Scale was applied in an office setting by a neurologist in 3 different centers. Stigma scores were calculated as standardized *T* scores (total, enacted, and internalized). Demographics, clinical characteristics, and treatment status of the patients were also compared in terms of stigma scores. Kruskal–Wallis test or Mann–Whitney *U* tests were applied for comparisons. Spearman's correlation analysis was used for the evaluation of inter-parameter correlations.

Results Eighty-one percent of the patients with epilepsy and 72% of the patients with migraine reported being stigmatized. Total *T* scores were significantly higher in the epilepsy group (50.78 ± 9.1) than the patients with migraine (44.9 ± 7.62), also than the chronic (45.86 ± 8.76) and episodic (44.7 ± 7.27) migraine subgroups ($p < 0.05$). *T* scores increased as the duration of disease increased; however, this correlation was significant for the epilepsy group only ($p < 0.05$). Migraine group with prophylactic treatment had significantly higher scores than the migraineurs without preventive therapy ($p < 0.05$). Enacted *T* scores were higher than internalized *T* scores in all analyzed groups and subgroups ($p < 0.05$).

Conclusion Patients with migraine and epilepsy are subjected to stigma. The ratio and intensity can change in different countries. We need to increase the awareness and search for better solutions. The standardized tests are important to compare results between studies.

Keywords Stigma · Migraine · Epilepsy · Neuro-QoL

Introduction

Stigma can be defined as negative labeling and stereotyping of individuals that can result in isolation, discrimination, loss of status, and diminished self-esteem [1–3]. Stigma in general can have a negative impact on many different aspects of life such as social relationships, employment status, and asking for or receiving adequate care when needed. There are increasing number of studies researching stigma due to different medical conditions [1–5].

Patients with neurological diagnoses can be a potential target for stigmatization. This may occur due to loss of function and sometimes, as in the case of epilepsy, due to sociocultural factors and beliefs associated with the disease [2–6].

✉ Fulya Basoglu Koseahmet
fbasoglu_crh@hotmail.com

Burcu Polat
burcupolat@medipol.edu.tr

Isil Baytekin
isilbaytekin@gmail.com

Muazzez Gokcen Soylu
gokcen3@hotmail.com; gokcenkarahan@gmail.com

Ayten Ceyhan Dirican
aytendirican@yahoo.com

Musa Ozturk
musaozturk2001@yahoo.com

[1] Department of Neurology, Bursa Cekirge Public Hospital, Bursa, Turkey

[2] Department of Neurology, Istanbul Medipol University, Istanbul, Turkey

[3] Department of Neurology, University of Health Sciences Bakirkoy Prof. Dr. Mazhar Osman Research and Training Hospital for Psychiatry, Neurology and Neurosurgery, Istanbul, Turkey

Published online: 15 January 2022

Migraine and epilepsy are two major neurological disorders that have a chronic course, causing reduced quality of life, loss of productivity, and difficulties in personal or professional life which can lead to stigmatization. Migraine is defined by recurrent headache attacks and associated symptoms that could not be better explained by the presence of another diagnosis [7]. This condition can affect people in different age groups, but commonly young to middle aged adults who are in their most productive years.

Epilepsy is a brain disorder characterized by epileptic seizures and by the neurological, psychological, and social consequences generated by this condition [8]. Idiopathic generalized epilepsy (IGE) is a well-known subgroup of epilepsy. These individuals have normal background EEG activity with generalized inter-ictal discharges and no underlying brain lesions [9, 10].

Migraine prevalence was found 15% in the USA and the highest prevalence was in the age group of 30–39 years (20.1%) [11]. In Turkey, estimated migraine prevalence is around 16.4% similar to previous data [12].

Global Burden of Disease Study 2016 estimated that, there were 1.04 billion (95% uncertainty interval [UI] 1·00–1·09) individuals with migraine around the world which corresponded to 45.1 million (95% UI 29·0–62·8) years of life lived with disability (YLDs). Although tension type headache affected a larger population (estimated 1.8 billion people (95% UI 1·71–2·10), it caused 7.2 million (95% UI 4·6–10·5) YLDs worldwide in 2016 [13].

The lifetime prevalence of epilepsy was found 7.60 per 1.000 population (95% CI 6.17–9.38) in Fiest et al.'s report. The incidence was higher in the youngest and in the oldest age groups [14]. In Turkey, epilepsy prevalence was reported around 8.5–10.2 per 1000 population in different studies [15, 16]. According to the 2016 Global Burden of Disease Collaborators, epilepsy was estimated to affect about 46 million people around the world. It caused more than 13 million disability-adjusted life-years (DALYs) and was accountable for 0.5% of the total disease burden [17].

Stigma in epilepsy is a relatively better known and studied phenomenon; however, there are very limited number of reports on stigma in primary headache disorders such as migraine. In the literature, the researchers used different questionnaires or created their own sets of questions. The standardized testing methods are more favorable because they provide quantifiable measurements and comparable scientific results [6, 18–21].

In this study, we aimed to investigate stigma in our migraine (including subgroups as episodic or chronic migraine) and idiopathic generalized epilepsy (IGE) patients with the Stigma Scale for Chronic Illness (SSCI) which was later renamed as Neuro-QoL Stigma Scale [4, 22]. We hypothesized that significant majority of the patients with migraine and epilepsy were subjected to stigmatization and the patients with migraine can have results close to people with epilepsy in terms of the severity of stigmatization. Data regarding demographics, clinical features, and treatment status of the patients were collected in order to compare with Neuro-QoL Stigma scores and to search for possible facilitating factors.

Method

Ethics approval

This study was approved by Ethics Committee with project no: 548, on July the 2nd, 2020. The study was performed in accordance with the Declaration of Helsinki and the institutional review board-approved protocols for human study participants at Istanbul Medipol University.

Patient selection

Patients over 18 years from three different neurology clinics, two from Istanbul and one from Bursa, were enrolled in the study on a voluntary basis.

The diagnosis of migraine was made according to the International Classification of Headache Disorders (ICHD)-3 criteria and the patients were divided into episodic and chronic migraine subgroups [7]. The diagnosis of IGE was made according to the International League Against Epilepsy (ILAE) 2017 revised criteria. Seizure types for epilepsy group were classified as follows: absence, myoclonic, tonic, tonic–clonic, myoclonic plus tonic–clonic, absence plus tonic–clonic, tonic plus tonic–clonic seizures and others [8–10, 23].

Exclusion criteria included cognitive impairment or active psychotic illness that prevented participants from providing correct responses and written consents, a diagnosis of more than one of the disorders specified in the inclusion criteria, and another neurological diagnosis that affects daily life activities and/or require treatment (stroke, multiple sclerosis, Parkinson's disease etc.). Patients with oncological diseases and other non-neurological conditions that affect daily life activities such as heart failure, severe chronic obstructive pulmonary disease, and kidney failure were also excluded.

Questionnaire administration

Form sheets questioning demographic, clinical parameters, and Neuro-QoL Stigma Scale-Turkish version were administered in an office setting after obtaining verbal and written consent from the patients. One question regarding disclosure of monthly household income was optional to answer, and other questions were answered by all the

participants. The average number of migraine attacks and epileptic seizures during the previous 3 months was used to determine the monthly number of migraine attacks and epileptic seizures.

Neuro-QoL Stigma Scale

Neuro-QoL study was set out to explore and demonstrate health-related quality of life in patients with neurological diseases via standardized questionnaires regarding several different aspects of life with disease. Stigma section of this questionnaire consisted of 24 items, 13 of them reflected *self/internalized* stigma and 11 of them was related to *enacted* stigma. Self/internalized stigma can be explained as the feeling of stigmatization, i.e., *how they felt* like a burden or emotionally distant to others. Enacted stigma is described as actual life events which they *were subjected to* stigmatization such as social discrimination or loss of employment due to their illness [2, 4].

Neuro-QoL Stigma scores were calculated by summation of the scores (1 = never to 5 = always) given to each of the 24 questions in the scale and then were converted into *T* scores (50 is the mean and 10 is the standard deviation) [24]. *T* scores related to self/internalized stigma (*T* score-I) or enacted stigma (*T* score-E) were also documented and calculated for all the patients. The stigma test was compared between epilepsy and migraine groups. Higher *T* scores indicated higher intensity of stigmatization.

Statistical analysis

SPSS 24.0 program (IBM Corp. Released 2016. IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY: IBM Corp.) was used for statistical calculations. Since our data were not normally distributed, Kruskal–Wallis test or Mann–Whitney *U* tests were applied for comparisons, where necessary. Spearman's correlation analysis was used for the evaluation of inter-parameter correlations. *p* value was significant at 0.05. One hundred and ninety-six migraine and 60 epilepsy patients were included in the study. Post hoc power analysis was 0.99 at 0.8/large effect level (alpha = 0.05) [25].

Results

The study comprised of 196 individuals with migraine and 60 people with idiopathic generalized epilepsy. Table 1 elaborates on patients' demographics and *T* score distribution and Table 2 shows clinical features and treatment data for migraine and epilepsy groups.

Patients with migraine

Out of 196 migraine patients, 83.2% was female and 16.8% was male. The mean age was 34.83 ± 14.14 years. The mean disease duration of migraineurs was 9.5 ± 7.96 years (min: 0.5 year, max: 40 years). One hundred and fifty-five of the patients were diagnosed with episodic (79.1%) and 41 (20.9%) with chronic migraine (CM).

80.5% of CM group was female and the mean age was 35.95 ± 11.97 years. Eighty-four percent of the episodic migraine (EM) group was female and the mean age was 35.71 ± 10.98 years.

The mean *T* scores of the patients over 56 years of age were higher than other age groups, men had slightly higher scores than women, and the highest income group had higher scores than other income groups. These comparisons and other *T* score distributions according to demographic subgroups were not statistically significant ($p > 0.05$).

Stigma scores of EM and CM subgroups were compared. CM subgroup had slightly higher mean *T* scores than EM, however without reaching statistical significance ($p = 0.593$). There was also no significant difference between CM and EM subgroups regarding *T* score-I or *T* score-E comparisons. However, *T* score-E values were slightly higher than *T* score-I values in all migraine patients and subgroups (Table 3).

Migraineurs with prophylaxis had significantly higher *T* scores in comparison to the patients without prophylactic treatment ($p < 0.001$). The mean *T* score-I and *T* score-E calculations were also calculated for these subgroups and were found higher in patients with prophylactic treatment than the patients without. *T* score-E values were higher than *T* score-I values in both these subgroups (Table 3).

The patients with longer disease durations had higher *T* scores, however without reaching statistical significance ($p = 0.06$). The number of days with headache did not correlate to *T* scores in EM subgroup ($p = 0.810$). The patients with 11–15 days of analgesic intake (DAI) per month had the highest scores and patients with 0–1 DAI per month had the lowest scores, yet this also was not statistically significant ($p = 0.490$) (Table 4).

Patients with epilepsy

In the epilepsy group, 61.7% of the patients was female, 38.3% was male, and the mean age was 34.13 ± 13.24 years. The mean disease duration was 10.61 ± 8.29 years (min: 1 year, max: 36 years).

Men had slightly higher scores than women, and literate individuals had higher *T* scores than other education subgroups; however, these results and other *T* score comparisons according to demographic data subgroups were not statistically significant ($p > 0.05$).

Table 1 Demographic data of migraine and epilepsy patients and mean *T* scores

		Migraine *n*: 196	Migraine mean *T* score	Epilepsy *n*: 60	Epilepsy mean *T* score
Age (years)		34.83 ± 14.14		34.13 ± 13.24	
Age subgroups (years)	18–25	49	44.68	19	49.33
	26–35	50	43.80	16	49.14
	36–45	60	45.13	13	54.19
	46–55	28	46.13	6	50.23
	56–70	9	48.72	6	53.00
Gender	Female	163	44.96	37	50.28
	Male	33	45.13	23	51.61
Education status	Literate	3	44.90	18	54.97
	Elementary School	53	45.47	8	46.53
	Secondary school	13	45.23	8	47.95
	High school	36	45.38	13	48.78
	University	48	45.56	13	51.38
	Postgraduate education	43	43.37	0	
Occupation	Housewife	72	45.87	30	52.21
	Teacher	4	42.25	0	
	Civil servant	3	39.10	0	
	Student	14	43.93	8	45.26
	Private business employee	46	43.81	1	35.60
	Medical professional	39	45.75	5	49.48
	Private business owner	18	45.24	16	52.24
Monthly household income (Turkish Lira)	0–2000	2	44.79	25	52.79
	2001–5000	38	43.97	20	47.48
	5001–10.000	112	45.13	8	52.28
	> 10.000	44	45.24	5	52.46
	Unknown	9	46.85	2	48.70

Abbreviation: *n*, number

The patients with longer disease durations had higher *T* scores. This distribution was significant ($p = 0.039$) and showed weak positive correlation (correlation coefficient (CC) = 0.397, $p = 0.002$ at 99% confidence level) (Table 4).

Regarding seizure types, the highest mean *T* score was in myoclonic plus tonic–clonic seizure patients (54.13) followed by absence plus tonic–clonic seizures (52.32), and myoclonic seizures (52.10). The absence group had the lowest mean *T* scores (45.11). This distribution did not show statistical significance ($p = 0.173$) (Table 4).

T scores increased as the number of seizures per month increased. Kruskal–Wallis test detected a significant difference (0.003). Spearman's Rho test showed significant correlation (CC = 0.481, $p = 0.001$ at 99% confidence level) between these parameters (Table 4).

Comparisons between migraine and epilepsy patients

The mean age was similar for migraine and epilepsy groups (34.83 ± 14.14 vs. 34.13 ± 13.24 years). A higher percentage of migraine group than epilepsy group was female (83.2% vs. 61.7%) (Table 1).

The initial step of data analysis showed that 81% of the patients with epilepsy and 72% of migraineurs answered at least one question with a mark other than "1" (never).

The mean total *T* score of the patients with epilepsy was found significantly higher than the migraine group ($p < 0.001$). They had also significantly higher mean total *T* score when individuals with migraine were subdivided into CM and EM subgroups ($p < 0.001$).

Table 2 Clinical parameters of migraine and epilepsy patients

		Migraine (*n*: 196)	Migraine mean *T* scores	Epilepsy (*n*: 60)	Epilepsy mean *T* scores
Duration of disease (years)	0–5	83	43.99	20	46.97
	6–10	56	44.99	18	49.72
	11–15	23	43.70	7	54.11
	15–20	18	48.43	7	55.81
	> 21	16	48.14	8	55.44
Days with MHA per month	0–1	6	42.43	0	
	2–5	63	44.48	0	
	6–10	56	45.58	0	
	11–15	30	44.25	0	
	16–30	41	45.86	0	
Days of analgesic intake per month	0–1	13	42.99	0	
	2–5	84	44.18	0	
	6–10	49	45.02	0	
	11–15	23	47.05	0	
	16–30	27	46.63	0	
Type of seizure	Absence	0		9	45.11
	Myoclonic	0		13	52.10
	T-C	0		11	47.54
	Myoclonic plus T-C	0		20	54.13
	Absence plus T-C	0		5	52.32
	Tonic plus T-C	0		1	48.60
	Tonic			1	48.30
Number of seizures per month	0–1	0		23	46.33
	2–5	0		24	52.01
	6–10	0		11	56.51
	> 11	0		1	60.00
Prophylaxis	No	155	43.72	0	
	Yes	41	49.74	60	50.78

Abbreviation: *MHA*, migraine headache; *n*, number; *T-C*, tonic–clonic

Table 3 Mean *T* scores of all groups and migraine treatment subgroups for total, internalized, and enacted Neuro-QoL stigma calculations

		Total *T* score	Internalized *T* score	Enacted *T* score
Migraine (*n*: 196)		44.9 ± 7.62	44.24 ± 7.15	46.83 ± 7.35
CM (*n*: 41)		45.86 ± 8.76	45.27 ± 8.31	47.71 ± 8.3
EM (*n*: 155)		44.7 ± 7.27	43.97 ± 6.82	46.59 ± 7.09
Migraine — with prophylaxis		49.74 ± 8.15	48.71 ± 7.35	51.86 ± 8.41
Migraine — no prophylaxis		43.72 ± 6.97	43.06 ± 6.64	45.5 ± 6.45
Epilepsy (*n*: 60)		50.78 ± 9.14	49.11 ± 8.04	53.46 ± 9.46
p value	Migraine vs epilepsy	< 0.001*	< 0.001*	< 0.001*
	Epilepsy vs CM vs EM	< 0.001**	< 0.001**	< 0.001**
	CM vs EM	NS*	NS*	NS*
	Migraine with prophylaxis vs no prophylaxis	< 0.001*	< 0.001*	< 0.001*

*Mann–Whitney *U* test (2-tailed)

**Kruskal–Wallis test

Abbreviations: *n*, number; *NS*, non-significant; *CM*, chronic migraine; *EM*, episodic migraine

Table 4 Comparisons of mean total *T* scores of the patients regarding clinical parameters

Diagnosis	Clinical parameters	*p* value
Migraine	Duration of disease	0.060**
	DAI per month	0.490**
	Days with HA per month	0.810**
Epilepsy	Duration of disease	0.039** 0.002^{+} *(CC: 0.397)*
	Seizure type	0.173**
	Seizure per month	0.003** $<0.001^{+}$ *(CC: 0.481)*

**Kruskal–Wallis test

$^{+}$Spearman's Rho test correlation is significant at the 0.01 level (2-tailed)

Abbreviations: *CC*, correlation coefficient; *DAI*, days of analgesic intake; *HA*, migraine headache

T score-I and *T* score-E comparisons also showed higher *T* scores for epilepsy patients in comparison to all migraine patients and also to CM and EM subgroups ($p < 0.001$) (Table 3).

Discussion

Migraine and IGE are primary neurological conditions without evidence of a structural etiology and these patients usually do not have permanent or visible physical disability. However, these mostly "invisible" disabilities have an impact on people's lives. In fact, the stigmatization surrounding them could become a disabling cause itself.

In our study, the majority of the individuals with epilepsy and migraine reported facing stigma, which was more pronounced in the epilepsy group. In addition, our results implied that enacted stigmatization was relatively more prominent than internalized (self) stigmatization in our society.

There are increasing number of other reports looking into stigmatization of epilepsy and migraine patients. In a recent study by Paige et al., researchers conducted semi-structured qualitative interviews with 81 migraine patients as part of an intervention study (mindfulness-based stress reduction or headache education) and they concluded that migraine affects emotional health in many ways such as anxiety, depression, and resulting in frustration, guilt, and stigma [19].

Baybas et al. created questionnaires for stigma in epilepsy that included 32 questions for the patients and 20 questions for the patients' relatives and found out that both parties experience epilepsy-related stigma and its complications such as social discrimination and isolation [20].

Only a few reports can be found in the literature where both epilepsy and migraine patients were enrolled and compared in terms of stigmatization. Aydemir et al. compared epilepsy (*n*: 70) and migraine patients (*n*: 56) regarding health-related quality of life, psychological well-being, impact of illness, and stigma. They also enrolled control subjects (*n*: 45) for parameters such as depression, health-related quality of life, and self-esteem. They applied a stigma scale by Jacob et al. and similar to our study, they found that people with epilepsy had higher stigmatization severity than the migraineurs [6, 26].

The European Federation of Neurological Associations (EFNA) Survey Report 2020 showed that, 92% of the patients with neurological diseases reported being affected by stigmatization. Among these patients, 96% (58% very much) of migraine/headache group (*n*: 186) and 86% (27% very much) of epilepsy group (*n*: 126) reported being stigmatized [3]. In our study, 81% of the patients with epilepsy and 72% of the migraineurs answered at least one question with an answer other than "never," this indicated being subjected to some level of stigmatization. These ratios were lower than EFNA Survey 2020 data also; our epilepsy group had higher severity of stigmatization than migraine group. These differences can be due to cultural factors.

We have found only one report by Young et al. which analyzed stigmatization of patients with migraine and epilepsy using the Neuro-QoL Stigma Scale [2]. They did not calculate the scores as *T* scores at that point in time. They found no statistical difference of scores in age, gender, education, and income subgroups for the migraine patients, which was in line with our results. Their scores for the epilepsy group were not different significantly in terms of gender as in our study. However, they found positive correlation with age and negative correlation with income and education status in the epilepsy group, and these effects were not observed in our study. Their adjusted raw scores were similar for CM subgroup and epilepsy group and lower for EM subgroup. Our epilepsy group had significantly higher scores than all migraine patients, CM and EM subgroups. CM patients had slightly higher mean *T* scores than EM patients but this was not statistically significant. This different tendency of stigmatization between our study and Young et al.'s study could be due to cultural and social background of different countries. However, further studies are needed for better clarification.

In Karsidag et al.'s 2019 study, out of 152 patients with different neurological diseases, 25 were patients with epilepsy and their mean *T* score was 49.1 ± 4.9, which is slightly lower than our epilepsy group (50.79 ± 9.1). They did not enroll patients with migraine so we could not compare this group, but they enrolled tension type headache group (*n*: 24) and their mean *T* score was 45.2 ± 2.8.

Interestingly, in our study, all the patient groups had higher *T* score-E than *T* score-I and the difference was the most prominent in the epilepsy group. This result implies that the external stigma burden is still important in these patients' lives. There is still room for improvement in education and awareness of their surroundings and society in general.

We noticed that, *T* scores increased as the duration of disease increased in both migraine and epilepsy groups, though this was statistically significant only for the epilepsy group ($p = 0.039$). This result is reasonable because, as the years pass, the effects of stigmatization can be expected to accumulate. In the migraine group, the results were close to being significant ($p = 0.060$) however was not; significance may be observed in larger sample groups.

T scores increased as the frequency of seizures increased in the epilepsy group, which was in line with our expectations. On the other hand, monthly number of headaches did not directly correlate with *T* scores in the migraine group although the individuals with 0–1 days with headache had the lowest scores and CM group had slightly higher scores than EM as mentioned previously. We may speculate that this is because the patients are orienting themselves to having headaches and after certain days per month, whereas in case of epilepsy, the patients seem to suffer from a more prominent burden regarding the frequency of the attacks. Socio-cultural elements may have played a role but more studies are needed to focus on these questions.

Migraine patients under prophylactic treatment had significantly higher *T* scores ($p < 0.001$) than the patients without preventive therapy. This may be because the patients experience more stigmatization (internalized and enacted) when they receive an everyday treatment for a disease so they could be labeled as "ill."

We selected idiopathic generalized epilepsy patients to create a relatively homogeneous group and to avoid possible stigmatization resulting from an underlying disease such as stroke and brain tumor. Stigma studies that focused on only one group of epilepsy or analyzed the effect of seizure types are scarce. We presumed that, the type of seizure might change stigmatization. For instance, an absence seizure would be less noticeable than a tonic–clonic attack in public. Therefore, we examined seizure subtypes and found that the patients with myoclonic plus tonic–clonic seizures had the highest mean *T* score and the absence group had the lowest. This distribution was not statistically significant ($p = 0.173$) in our study, and further studies with larger sample sizes are necessary. Still, it provides an insight that stigma of epilepsy affects people's lives differently and these differences should not be overlooked.

Our study was the first in Turkey that included both migraine and epilepsy groups to analyze stigmatization via Neuro-QoL Stigma Scale. Also, this was the first study to compare stigma in EM, CM, and epileptic seizure subgroups in our country.

Limitations

Our EM subgroup could have experienced CM sometime in their life and vice versa. The nature of migraine makes it difficult to distinguish between these two categories.

The therapy could not be standardized either. All the patients were under follow-up by a neurologist in a secondary or a tertiary hospital. All the patients with epilepsy received up-to-date anti-epileptic treatment. Around 19% of our EM patients and roughly 27% of CM subgroup received prophylactic treatment, which is low. Despite being exposed to preventive therapies, they either refused or dropped out after insufficient durations or doses. This might be another sign of stigmatization, as stated previously. To escape the illness designation, some people may have avoided regular therapy.

Conclusion

Stigma in migraine and epilepsy affects people's lives. This could extent from feeling isolated or bereaved to losing their employment due to their illness. We need to identify the issue and develop better tools to overcome this problem. An essential step might be educating medical professionals and the public. Each country can have different cultural and social factors that could affect stigmatization. The standardized tests are useful instruments to assess stigma since they provide quantifiable data and allow comparisons across research all around the world.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s10072-022-05888-1.

Declarations

Conflict of interest The authors declare no conflict of interests.

Ethical approval This study was approved by Ethics Committee with project no: 548, on July the 2nd, 2020. The study was performed in accordance with the Declaration of Helsinki and the institutional review board-approved protocols for human study participants at Istanbul Medipol University.

Informed consent Written informed consent was obtained from all participants.

References

1. Link BG, Phelan JC (2001) Conceptualizing stigma. Annu Rev Sociol 27(1):363–385
2. Young WB, Park JE, Tian IX, Kempner J (2013) The stigma of migraine. PLOS ONE 8(1):e54074. https://doi.org/10.1371/journal.pone.0054074
3. European Federation of Neurological Associations (EFNA). (July, 2020). Survey on stigma and neurological disorder results. Retrieved from https://www.efna.net/survey2020/ (last accessed at 10/26/21)
4. Rao D, Choi SW, Victorson D et al (2009) Measuring stigma across neurological conditions: the development of the stigma scale for chronic illness (SSCI). Qual Life Res 18(5):585–595. https://doi.org/10.1007/s11136-009-9475-1
5. Vilanilam G, Badi MK, Meschia JF (2018) Destigmatizing migraine. Cureus 10(5):e2711. https://doi.org/10.7759/cureus.2711
6. Aydemir N, Ozkara C, Unsal P, Canbeyli R (2011) A comparative study of health related quality of life, psychological well-being, impact of illness and stigma in epilepsy and migraine. Seizure 20(9):679–685. https://doi.org/10.1016/j.seizure.2011.06.017
7. Headache Classification Committee of the International Headache Society (IHS) (2013) The International Classification of Headache Disorders, 3rd edition (beta version). Cephalalgia 33(9):629–808. https://doi.org/10.1177/0333102413485658
8. Fisher RS, Acevedo C, Arzimanoglou A et al (2014) ILAE official report: a practical clinical definition of epilepsy. Epilepsia 55(4):475–482. https://doi.org/10.1111/epi.12550
9. Guerrini R, Marini C, Barba C (2019) Generalized epilepsies. Handb Clin Neurol 161:3–15. https://doi.org/10.1016/B978-0-444-64142-7.00038-2
10. Scheffer IE, Berkovic S, Capovilla G et al (2017) ILAE classification of the epilepsies: position paper of the ILAE Commission for Classification and Terminology. Epilepsia 58(4):512–521. https://doi.org/10.1111/epi.13709
11. Bigal ME, Libermann JN, Lipton RB (2006) Age-dependent prevalence and clinical features of migraine. Neurology 67:246–251
12. Ertas M, Baykan B, Orhan EK, Zarifoglu M et al (2012) One-year prevalence and the impact of migraine and tension-type headache in Turkey: a nationwide home-based study in adults. J Headache Pain 13(2):147–57
13. GBD 2016 Headache Collaborators (2018) Global, regional, and national burden of migraine and tension-type headache, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. Lancet Neurol 17(11):954–976. https://doi.org/10.1016/S1474-4422(18)30322-3
14. Fiest KM, Sauro KM, Wiebe S et al (2017) Prevalence and incidence of epilepsy: a systematic review and meta-analysis of international studies. Neurology 88(3):296–303
15. Calişir N, Bora I, Irgil E, Boz M (2006) Prevalence of epilepsy in Bursa city center, an urban area of Turkey. Epilepsia 47(10):1691–1699. https://doi.org/10.1111/j.1528-1167.2006.00635.x
16. Karaagaç N, Yeni SN, Senocak M (1999) Bozluolçay M et al Prevalence of epilepsy in Silivri, a rural area of Turkey. Epilepsia 40(5):637–642. https://doi.org/10.1111/j.1528-1157
17. GBD 2016 Epilepsy Collaborators (2019) Global, regional, and national burden of epilepsy, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. Lancet Neurol 18(4):357–375. https://doi.org/10.1016/S1474-4422(18)30454-X
18. Prakash S (2016) Patients with tension-type headaches feel stigmatized. Ann Indian Acad Neurol 19(1):112–114. https://doi.org/10.4103/0972-2327.168640
19. Paige M, Estave PhD, Beeghly S et al (2021) Learning the full impact of migraine through patient voices: a qualitative study. Headache 23(92):76–81
20. Baybaş S, Yıldırım Z, Ertem DH et al (2017) Development and validation of the stigma scale for epilepsy in Turkey. Epilepsy Behav 67:84–90. https://doi.org/10.1016/j.yebeh.2016.12.023
21. Wei Z, Ren L, Yang L et al (2021) The relationship between social anxiety and felt stigma in patients with epilepsy: a network analysis. Seizure 23(92):76–81. https://doi.org/10.1016/j.seizure.2021.08.014
22. Karşıdağ S, Çınar N, Şahin Ş (2019) Validation and reliability study of the Turkish version of the Neuroquality of Life (Neuro-QoL)-Stigma Scale for neurological disorders. Turk J Med Sci 49(3):789–794. https://doi.org/10.3906/sag-1811-50
23. Fisher RS, Cross JH, D'Souza C et al (2017) Instruction manual for the ILAE 2017 operational classification of seizure types. Epilepsia 58(4):531–542. https://doi.org/10.1111/epi.13671
24. National Institute of Neurological Disorders and Stroke (NINDS) User Manual for the Quality of Life in Neurological Disorders (Neuro-QoL) Measures, Version 2.0, March 2015. Retrieved from https://www.healthmeasures.net/explore-measurement-systems/neuro-qol. Accessed 26 Oct 2021
25. Cohen J (1988) Statistical power analysis for the behavioral sciences, 2nd edn. Lawrence Erlbaum Associates, Publishers, Hillsdale
26. Jacoby A (1994) Felt versus enacted stigma: a concept revisited evidence from a study of people with epilepsy in remission. Soc Sci Med 38(2):269–274