Does the new Korean term for epilepsy reduce the stigma for Korean adults with epilepsy?

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ABSTRACT

Purpose: The purpose of this study was to evaluate differences in stigma, disclosure management of epilepsy, and knowledge about epilepsy between patients with epilepsy who recognized and did not recognize the new Korean term for epilepsy.
Methods: This was a cross-sectional, multicenter study. The Stigma Scale-Revised, the Disclosure Management Scale, the Patient Health Questionnaire-9, and a questionnaire assessing knowledge about epilepsy were used. The set of questionnaires had two versions, using either the old or new name for epilepsy. Multivariate logistic regression analyses were used.
Results: A total of 341 patients with epilepsy and 509 family members were recruited. Approximately 62% of patients felt some degree of epilepsy-related stigma. Mild stigma, severe concealment of epilepsy diagnosis, and increased knowledge about epilepsy were independently identified as factors associated with recognition of the new term in patients. Recognition of the new term was more prevalent in patients and family members with higher education, female family members, and family members having patients with younger age at seizure onset and shorter duration of epilepsy. There were no significant differences between the two types of questionnaires. About 81% of patients and 93% of family members had a positive attitude about renaming epilepsy.
Conclusion: The use of the new Korean term for epilepsy (cerebroelectric disorder) increased knowledge about

epilepsy but did not reduce stigma and concealment of epilepsy diagnosis in Korean adults with epilepsy. Higher education may be an important factor for knowing the new term in patients and family members.

1. Introduction

Epilepsy is one of the first described neurological diseases and is considered a stigmatizing condition [1]. In spite of the teachings of Hippocrates (460–370 BC) that epilepsy is a physical illness, misconceptions regarding the cause of epilepsy became predominant in the Middle Ages [2]. Currently, misconceptions regarding epilepsy have nearly disappeared or are rapidly declining worldwide [3]. However, patients with epilepsy continue to suffer from stigma, as well as social restriction and discrimination, in everyday activities, such as going to school, driving, working, and obtaining insurance [4–6], not only in the developing world but also in the West [4]. In a large European study, half of patients with epilepsy experienced feelings of stigma associated with epilepsy diagnosis [7]. This perception significantly impacts the quality of life of patients with epilepsy [4,7,8].

It is unclear whether the terminology used to describe epilepsy influences our perceptions of the diseases or affects its social stigma [9,10]. In Korea, as a potential strategy to reduce the stigma of epilepsy, the Korean term for epilepsy was renamed from *gan-jil* (간질, 癇疾) to *noi-jeon-jeung* (뇌전증, 腦電症) in the year 2011 [11]. The new term, '*noi-jeon-jeung*', means 'cerebroelectric disorder' and was chosen because it reflects the pathophysiology of the disease and can prevent misconceptions about epilepsy. After renaming the Korean term for epilepsy, efforts have been made to introduce the new Korean term to the public through activities, such as public education, media, and social campaigns. Now, 8 years later, the Korean Epilepsy Society sought to determine if renaming epilepsy improved stigma-related outcomes in the public, including negative public attitudes toward epilepsy and patients with epilepsy. In a recent study, however, the new Korean term was used in only 26% of total internet searches for epilepsy using Naver from January 2016 to April 2018 in Korea [12]. This degree of dissemination for the new name in the public was not satisfactory and was not considered sufficient to evaluate changes in public attitudes toward epilepsy in Korea.

Therefore, the present study sought to determine how patients with epilepsy and their family members responded to renaming the Korean term for epilepsy. The aim was to determine 1) whether there are differences in perceived stigma, disclosure management of epilepsy diagnosis, depressive symptoms, and knowledge about epilepsy depending on whether patients with epilepsy and patient family members knew the new Korean term for epilepsy and 2) which factors are associated with recognition of the new Korean term in patients with epilepsy and family members. In addition, we also determined whether there were differences between two types of questionnaires using the new and old terms in patients who knew the new Korean term for epilepsy.

2. Methods

2.1. Subjects

This was a cross-sectional, multicenter study involving the departments of neurology and pediatric neurology of 22 university hospitals in Korea. Data were collected from adults with epilepsy and family members of adult and pediatric patients with epilepsy. Patients over 19 years of age with a diagnosis of epilepsy were eligible for inclusion. Family members who were the first-degree relatives of patients with epilepsy and were aged 19–65 years of age were allowed to participate. Patients were excluded if age at seizure onset was over 65 years of age or if they had experienced a seizure in the 72 h prior to study enrollment. Patients and family members who had difficulty with conversation or written communication were also excluded. The revised 2014 definition of epilepsy and the new classification of seizures and epilepsy were applied [13–15].

Participants were asked to identify the new Korean term for epilepsy among nine terms for neurological and mental conditions and were categorized into two groups depending on whether they knew the new Korean term for epilepsy (recognition vs. nonrecognition groups). Patients with epilepsy were asked to fill out a set of questionnaires using the old or new term on the day they visited an outpatient clinic. Demographic and clinical data were collected by interview and by reviewing each patient's medical record files. Written informed consent was obtained from all participants. The study was reviewed and approved by the Institutional Review Board of Asan Medical Center.

2.2. Measures

The set of questionnaires had two versions, version A using the old Korean term for epilepsy and version B using the new Korean term for epilepsy. The contents of the questionnaires were identical in both versions except the term for epilepsy. Patients from the recognition group randomly received one of two versions with a ratio of A:B equal to 1:2, and patients from the nonrecognition group received only version A. The questionnaires included the Stigma Scale-Revised (SS-R) and the Disclosure Management Scale (DMS).

The SS-R for epilepsy is a three-item self-reported scale that includes questions regarding how much patients feel other people are uncomfortable with them, treated them as inferior, or preferred to avoid them because they have the condition of epilepsy [16]. A four-point Likert-type scale is used to rate each item (0 = not at all; 1 = yes, maybe; 2 = yes, probably; 3 = yes, definitely), with total scores ranging from 0 to 9. Patients were categorized as experiencing no (score of 0), mild (scores of 1–3), and moderate-to-severe (scores of 4–9) stigma [16].

The DMS is a four-item self-reported scale, including the following questions: 1) Do you keep your epilepsy a secret from others? 2) Do any of your friends know that you have epilepsy? 3) When people find out you have epilepsy, is it usually because you tell them, because you have a seizure and then have to explain it, because you have a seizure and then they see you having a seizure, or because someone else tells them? and 4) How often do you talk to people about your epilepsy? [17]. Each item is rated on a four-point Likert-type scale, ranging from 0 (no concealment of epilepsy) to 3 (full concealment of epilepsy). The score was added across all items to produce a cumulative score ranging from 0 to 12. The DMS scores were categorized into no or mild (scores of 0–3), moderate (scores of 4–6), and severe (scores of 7–12) concealment of epilepsy diagnosis [17].

In addition, patients with epilepsy and family members were asked to fill out the Patient Health Questionnaire-9 (PHQ-9), the questionnaire for knowledge about epilepsy, and a question about their attitude toward renaming epilepsy.

The PHQ-9 is a nine-item self-reported scale and evaluates each of the nine Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) criteria for major depressive disorder [18]. Each item is rated on a four-point Likert scale, ranging from 0 (absence of symptom) to 3 (presence of symptom nearly every day) in the last 2 weeks. A total PHQ-9 score ranges from 0 to 27, with a PHQ-9 score ≥10 indicative of depression [19].

Knowledge about epilepsy was assessed by seven questions, each requiring a simple true/false response, including knowledge of the features, etiology, and treatment of epilepsy (organic brain disease, mental illness, inheritable disease, transmissible disease, occurring at any age, incurable disease, and curable by surgery) [20]. Participants receive one point for each item they answer correctly, and their overall score is the sum of their correct responses, ranging from 0 to 7. The level of knowledge about epilepsy was categorized into low (scores of 0–3), moderate (scores of 4–5), and high (scores of 6–7).

Participants' attitude toward renaming epilepsy was assessed by one question, "Do you think that renaming of the term *gan-jil* (간질, 癎疾) to *noi-jeon-jeung* (뇌전증, 腦電症, cerebroelectric disorder) is meaningful?" This question required a simple yes/no response.

2.3. Statistical analysis

The demographic and clinical characteristics between recognition and nonrecognition groups were compared. Data are presented as means ± standard deviation (SD) for numeric variables and numbers and percentages for nominal variables. Student's *t*-tests, analyses of variance, and chi-square tests were used for univariate analyses. The potential factors independently associated with recognition of the new Korean term for epilepsy were assessed in patients and family members using multivariate logistic regression analyses. The dependent variable was the status of recognition of the new term. Independent variables included level of perceived stigma (only for patients), level of disclosure management (only for patients), depressive symptoms, and level of knowledge about epilepsy. Adjusting variables included age, gender, level of education, relation to patients (only for family members), and epilepsy-related variables. Epilepsy-related variables included age at seizure onset, duration of epilepsy, type of epilepsy and seizures, seizure frequency in the last year, recurrence of generalized or focal-to-bilateral tonic–clonic seizures in the last year, number of antiepileptic drugs, and comorbidities with epilepsy. Variables with $p < 0.1$ on univariate analysis with age and gender were then entered into multivariate logistic regression models to assess variables associated with recognition of the new name. The calibration power of each model was assessed using the Hosmer–Lemeshow goodness of fit test, and $p > 0.05$ indicated a well-calibrated model. A concordance statistic (c-statistic) was calculated. The c-statistics assessed the discrimination of the model (i.e., the ability of the model to distinguish between participants who knew the new term for epilepsy from those who did not). In addition, the demographic and clinical characteristics between version A and B questionnaires in patients with epilepsy who knew the new term for epilepsy were compared. All statistical tests were two-tailed, and $p < 0.05$ was considered significant. Data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 21.0 (International Business Machines Corp., Armonk, NY, USA).

Table 1
Patient characteristics and comparisons between patients who did and did not know the new Korean term for epilepsy (n = 341).

	Total	Knowing the new term for epilepsy	
		No (n = 111)	Yes (n = 230)
Gender, female, n (%)	143 (41.9)	40 (36.7)	103 (46.0)
Age, years, mean (SD)	37.2 (13.0)	40.7 (14.4)	35.5 (11.9)[**]
Education, n (%)			
Middle school	27 (8.3)	19 (18.4)	8 (3.6)[***]
High school	101 (30.9)	36 (35.0)	65 (29.0)
University	199 (60.9)	48 (46.6)	151 (67.4)
Knowledge about epilepsy, n (%)			
Low (score 0–3)	76 (22.3)	36 (32.4)	40 (17.4)[**]
Middle (score 4–5)	146 (42.8)	48 (43.2)	98 (42.6)
High (score 6–7)	119 (34.9)	27 (24.3)	92 (40.0)
Stigma Scale-Revised, n (%)			
Score = 0	129 (37.8)	50 (45.0)	79 (34.3)[*]
Score 1–3	143 (41.9)	36 (32.4)	107 (46.5)
Score ≥4	69 (20.2)	25 (22.5)	44 (19.1)
Disclosure Management Scale, n (%)			
Score 0–3	69 (20.2)	28 (25.2)	41 (17.8)[*]
Score 4–6	131 (38.4)	50 (45.0)	81 (35.2)
Score ≥7	141 (41.3)	33 (29.7)	108 (47.0)
PHQ-9 score ≥10, n (%)	70 (20.5)	25 (22.5)	45 (19.7)
Age at seizure onset, years, mean (SD)	22.6 (13.5)	25.4 (15.6)	21.2 (12.2)[**]
Duration of epilepsy, years, mean (SD)	14.5 (11.8)	15.0 (12.1)	14.2 (11.8)
Epilepsy type, n (%)			
Generalized	56 (16.4)	13 (11.7)	43 (18.8)
Focal	241 (70.7)	88 (79.3)	153 (66.8)
Unknown	44 (12.9)	10 (9.0)	33 (14.4)
Predominant seizure type, n (%)			
Focal aware	46 (13.5)	10 (9.3)	36 (16.0)
Focal impaired awareness	89 (26.1)	33 (30.8)	56 (24.9)
Generalized TCS or FBTCS	197 (57.8)	64 (59.8)	133 (59.1)
Seizure frequency in the last year, n (%)			
Seizure-free	93 (38.1)	37 (33.6)	93 (40.8)
<1/month	162 (47.5)	55 (50.0)	107 (46.9)
≥1/month	46 (13.5)	18 (16.4)	28 (12.3)
Generalized TCS or FBTCS in the last year, n (%)	114 (34.3)	40 (36.7)	74 (33.2)
Antiepileptic drug polytherapy, n (%)	198 (58.6)	69 (63.3)	129 (56.3)
Comorbidities, n (%)	54 (15.8)	26 (23.4)	28 (12.2)[**]

FBTCS, focal-to-bilateral tonic–clonic seizures; PHQ-9, Patient Health Questionnaire-9; SD, standard deviation; TCS, tonic–clonic seizures.
The range of possible scores of the measures: knowledge about epilepsy, 0–7; Stigma Scale-Revised, 0–9; Disclosure Management Scale, 0–12; and PHQ-9, 0–27.
 * $p < 0.05$.
 ** $p < 0.01$.
 *** $p < 0.001$.

3. Results

3.1. Subject characteristics

A total of 341 patients with epilepsy were included (42.9% female), with a mean age of 37.2 years (SD: 13.0) (Table 1). More than 90% of patients had at least 12 years of education. The majority (70.9%) had focal epilepsy, and more than one-third (38.5%) had no seizure recurrence in the last year. Depressive symptoms (PHQ-9 score: ≥10) were noted in 20.5% of patients. About 62% of patients felt some degree of epilepsy-related stigma. Comorbidities with epilepsy were noted in 54 (15.8%) patients (psychiatric, 18; neurological, 12; and other conditions, 24). The majority of patients (80.6%) had a positive attitude toward renaming epilepsy. Of 341 patients, 108 (31.7%) participated in the study with their one family member.

A total of 509 family members of patients with epilepsy were included (74.1% female), with a mean age of 47.2 years (SD: 9.5) (Table 2). Relationship to the patient included parents (n = 377; 74.1%), spouse (n = 79; 15.5%), sibling (n = 31; 6.1%), and son or daughter (n = 22; 4.3%). More than 90% of family members had at least 12 years of education. Depressive symptoms (PHQ-9 score: ≥10) were noted in 10.6% of family members. The majority of family members (92.7%) had a positive attitude toward renaming epilepsy. With regard to the epilepsy of their family member, focal epilepsy and seizure freedom in the last year were noted in 65.4% and 37.6% of participants, respectively. Comorbidities with epilepsy were noted in 166 (32.6%) patients (psychiatric, 21; intellectual disability, 74; neurological, 62; and other conditions, 9).

3.2. Factors associated with recognition of the new Korean term for epilepsy in patients with epilepsy

Univariate analyses demonstrated that recognition of the new term was significantly associated with younger age, higher level of education, increased knowledge about epilepsy, increased perceived stigma, increased concealment of epilepsy diagnosis, younger age at seizure onset, and presence of comorbidities with epilepsy (Table 1). The types of epilepsy did not reach statistical significance (p < 0.1). Based on logistic regression analysis (Table 3), mild perceived stigma (SS-R: 1–3), severe concealment of epilepsy diagnosis (DMS: ≥7), high level of knowledge about epilepsy (score: 6–7), and high levels of education (high school and university) were identified as independent factors associated with recognition of the new term. Female gender and presence of comorbidities did not reach statistical significance (p < 0.1). The Hosmer–Lemeshow test revealed that the model fits well (p = 0.281) and the model for recognition of the new term had acceptable discrimination (c-statistic of 0.754).

3.3. Factors associated with recognition of the new Korean term in family members

Univariate analyses demonstrated that recognition of the new term was significantly associated with female gender, younger age, higher level of education, relation to the patient (parents), higher level of knowledge about epilepsy, younger age group of patients, younger age at seizure onset, and shorter duration of epilepsy (Table 2). Based on logistic regression analysis (Table 4), female gender, university education level, high level of knowledge about epilepsy (score: 6–7), younger age at seizure onset, and shorter duration of epilepsy were identified as independent factors associated with recognition of the new term in family members. The Hosmer–Lemeshow test revealed that the model fits well (p = 0.328) and the model for recognition of the new term had acceptable discrimination (c-statistic of 0.790).

3.4. Comparisons of psychological variables between version A and B questionnaires

Univariate analyses showed that there were no differences in perceived stigma and concealment of epilepsy diagnosis between the different versions of questionnaires used in patients who recognized the new Korean term for epilepsy (Table 5).

4. Discussion

The present study identified that in Korea, patients with epilepsy who recognized the new Korean term for epilepsy had higher knowledge about epilepsy but had more severe perceived stigma and more frequent concealment of epilepsy diagnosis than those who did not. These findings were adjusted for age, gender, level of education, and epilepsy-related variables. Family members who recognized the new term also had higher knowledge about epilepsy. Recognition of the new term was more prevalent in patients and family members with higher education, female family members, and family members having patients with younger age at seizure onset and shorter duration of epilepsy. In addition, there were no differences between the two types of questionnaires using the new and old terms in patients with epilepsy who knew the new Korean term for epilepsy.

Lack of knowledge about epilepsy is considered the factor most consistently associated with negative public attitudes [9]. In patients with epilepsy themselves, lack of knowledge about epilepsy is also associated with increased perceived stigma and depressive symptoms [21–23]. In the present study, recognition of the new term for epilepsy was significantly associated with higher knowledge about epilepsy in both patients and family members. In this cross-sectional study, causal relationships between variables were not determined. Given that the new Korean term, 'noi-jeon-jeung', literally means 'cerebroelectric disorder' and reflects the pathophysiology characterized by abnormal electrical discharges in the brain [11], it is possible that increased epilepsy knowledge is the effect of renaming epilepsy in Korea. Renaming schizophrenia in Japan has shown inconsistent results regarding knowledge outcomes [10]. One Japanese study of university students reported that the new term (integration disorder) was associated with more accurate knowledge about schizophrenia compared with the old term (mind-split disease) [24], but another study of Japanese family members of patients with schizophrenia did not find the same significant relationship [25]. Improving knowledge about the condition is important to help patients with the disease to cope with their diagnosis, which, in turn, may prevent generation of perceived stigma [1].

The objective of renaming the disease was to reduce the stigma associated with the term epilepsy and ultimately improve quality of life in patients with epilepsy. However, the present study did not suggest that renaming epilepsy had the effect of reducing perceived stigma in patients with epilepsy. Rather, recognition of the new term was significantly associated with more perceived stigma and more frequent concealment of epilepsy diagnosis. These findings were unlikely to be due to negative effects of renaming epilepsy. Rather, persons who are stigmatized by their epilepsy are more likely to seek means to avoid discrimination by society and consequently to recognize the new term. The new Korean term (cerebroelectric disorder) is not yet commonly used in our society [12] and therefore does not elicit negative images of patients with epilepsy. Unlike other studies [26,27] in which public attitudes toward patients with epilepsy were assessed by using questionnaires with different labels for a hypothetical patient with epilepsy, this study recruited patients living with epilepsy and assessed their feelings and experiences connected with their factual condition using a questionnaire with two different terms. Therefore, the choice of wording can be expected to have a much lesser impact on stigma of epilepsy in patients with epilepsy than in the general public. Most of the patients and family members in this study showed positive attitudes toward renaming the term for epilepsy.

Although renaming epilepsy in Korea was not found to reduce perceived stigma in patients with epilepsy in this study, our findings do not rule out the possibility that renaming epilepsy could have beneficial effects on public attitudes regarding epilepsy. There has been some debate regarding how the terminology used for epilepsy influences public attitudes toward the disease. In a Brazilian study [26] using different terms for referring to patients with epilepsy, high school students exhibited more negative attitudes toward patients with epilepsy when referring to these patients as 'epileptics' compared with referring to these patients as 'people with epilepsy'. However, a UK study did not replicate the finding that the word 'epileptic' provokes more negative attitudes in university students [9]. In a Croatian study with a sample of adolescents, the label 'epileptic' evoked more negative attitudes toward patients with epilepsy for intimate life domains (cohabitation or marriage) but not for impersonal domains such as communicating and working with patients with epilepsy [27]. These inconsistent findings suggest that influences of disease terminology on negative attitudes could be culturally dependent. Similarly, the impacts of the new term for schizophrenia are still inconclusive in Japan and some other Asian countries [10,24,25]. Overall, in countries where schizophrenia has been renamed, the name change may be associated with improvements in attitudes toward people with schizophrenia. However, studies conducted in countries where schizophrenia has not been renamed report inconsistent findings [10].

In this study, as expected, high educational level was one of the important factors independently associated with recognition of the new Korean term for epilepsy. Compared with those with middle school education, family members with university education level were four to five times more likely to recognize the new term whereas patients with university and high school education were 7.5 times and 4 times, respectively, more likely to do. Gender was also important to predict recognition of the new term. Female family members were about two times more likely to recognize the new term. However, female gender in patients with epilepsy did not reach statistical significance (p = 0.058). In addition, family members who had patients with younger age at seizure onset and shorter duration of epilepsy were more likely to know the new term.

There are some limitations in the present study, and the results should thus be interpreted with some caution. Firstly, the design of the study was cross-sectional, and we were therefore unable to determine causal relationships in our findings. Secondly, the study population was limited to patients with epilepsy and their family members recruited from university hospitals, and about 90% of the participants had a high school education or higher. Therefore, some of these findings

Table 2
Family members' characteristics and comparisons between family members who did and did not know the new Korean term for epilepsy (n = 509).

	Total	Knowing the new term for epilepsy	
		No (n = 111)	Yes (n = 398)
Family members			
Gender, female, n (%)	377 (74.1)	66 (59.5)	311 (78.1)[***]
Age, years, mean (SD)	47.2 (9.5)	49.2 (11.9)	46.6 (8.6)[*]
Education, n (%)			
Middle school	45 (8.8)	22 (21.4)	23 (5.9)[***]
High school	196 (38.5)	46 (44.7)	150 (38.5)
University	252 (49.5)	35 (34.0)	217 (55.6)
Relation to the patient, n (%)			
Parents	377 (74.1)	61 (55.0)	316 (79.4)[***]
Spouse	79 (15.5)	27 (24.3)	52 (13.1)
Sibling or offspring	53 (10.4)	23 (20.7)	30 (7.5)
Knowledge about epilepsy, n (%)			
Low (score 0–3)	72 (14.1)	32 (29.1)	40 (10.1)[***]
Middle (score 4–5)	247 (48.5)	59 (53.6)	188 (47.2)
High (score 6–7)	189 (37.1)	19 (17.3)	170 (42.7)
PHQ-9 score ≥10, n (%)	54 (10.6)	10 (9.2)	44 (11.3)
Patients with epilepsy			
Gender, male, n (%)	275 (54.0)	63 (56.8)	212 (54.1)
Age group, n (%)			
≤19 years	238 (46.8)	29 (26.1)	209 (52.5)[***]
20–39 years	169 (33.2)	38 (34.2)	131 (32.9)
≥40 years	102 (20.2)	44 (39.6)	58 (14.6)
Age at seizure onset, years, mean (SD)	15.1 (14.1)	20.4 (17.8)	13.6 (12.4)[***]
Duration of epilepsy, years, mean (SD)	10.9 (10.7)	15.0 (12.0)	9.0 (9.4)[***]
Epilepsy type, n (%)			
Generalized	115 (22.6)	22 (19.8)	93 (23.4)
Focal	333 (65.4)	75 (67.6)	258 (64.8)
Unknown	61 (12.0)	14 (12.6)	44 (11.8)
Predominant seizure type, n (%)			
Focal aware	36 (7.1)	6 (5.9)	30 (7.8)
Focal impaired awareness	173 (34.0)	41 (40.2)	132 (34.2)
Generalized TCS or FBTCS	279 (54.8)	55 (53.9)	224 (58.0)
Seizure frequency in the last year, n (%)			
Seizure-free	189 (37.1)	45 (41.7)	144 (36.5)
<1/month	219 (43.0)	46 (42.6)	173 (43.8)
≥1/month	95 (18.7)	17 (15.7)	78 (19.7)
Generalized TCS or FBTCS in the last year, n (%)	188 (36.9)	37 (33.9)	151 (38.7)
Antiepileptic drug polytherapy, n (%)	298 (58.5)	64 (58.7)	234 (59.1)
Comorbidities, n (%)	166 (32.6)	34 (30.6)	132 (33.2)

FBTCS, focal-to-bilateral tonic–clonic seizures; PHQ-9, Patient Health Questionnaire-9; SD, standard deviation; TCS, tonic–clonic seizures.
The range of possible scores of the measures: knowledge about epilepsy, 0–7 and PHQ-9, 0–27.
  * p < 0.05.
 *** p < 0.001.

Table 3

Multiple logistic regression analysis for the factors associated with recognition of the new Korean term for epilepsy in patients with epilepsy.

	Adult patient group (n = 341)		
	Knowing the new term for epilepsy		
	OR	95% CI	p value
Independent variables			
Stigma Scale-Revised score 1–3[a]	1.900	1.046–3.452	0.035
Stigma Scale-Revised score ≥4[a]	1.248	0.601–2.592	0.553
Disclosure Management Scale score 4–6[b]	1.173	0.595–2.313	0.644
Disclosure Management Scale score ≥7[b]	2.761	1.324–5.758	0.007
Knowledge about epilepsy score 4–5[c]	1.542	0.787–3.023	0.207
Knowledge about epilepsy score 6–7[c]	2.491	1.201–5.164	0.014
Adjusted variables			
Age, years	0.991	0.962–1.020	0.529
Gender, female	1.636	0.928–2.882	0.089
Education, high school[d]	4.004	1.442–11.118	0.008
Education, university[d]	6.704	2.354–19.089	0.000
No comorbidities with epilepsy	1.856	0.893–3.857	0.098
Age at seizure onset, years	0.998	0.974–1.023	0.898
Focal epilepsy[e]	0.715	0.321–1.589	0.410
Unknown epilepsy[e]	1.238	0.412–3.717	0.704

CI, confidence interval; OR, odds ratio.

The range of possible scores of the measures: Stigma Scale-Revised, 0–9; Disclosure Management Scale, 0–12; and knowledge about epilepsy, 0–7.

[a] Reference: Stigma Scale-Revised score = 0.
[b] Reference: Disclosure Management Scale score 0–3.
[c] Reference: knowledge about epilepsy score 0–3.
[d] Reference: education, middle school.
[e] Reference: generalized epilepsy.

may not be generalizable to all patients with epilepsy and their family members. Thirdly, the use of self-reporting scales, which can allow for response bias, may also be a limiting factor. Finally, the results were partly influenced by cultural and language backgrounds, so some of the findings might not be generalizable to other countries.

In conclusion, the present study demonstrated that recognition of the new Korean term for epilepsy (cerebroelectric disorder) was significantly associated with higher knowledge about epilepsy but did not suggest that renaming epilepsy reduced perceived stigma, concealment of epilepsy diagnosis, or depressive symptoms. Future studies are

Table 4

Multiple logistic regression analysis for the factors associated with recognition of the new Korean term for epilepsy in family members of patients with epilepsy.

	Family member group (n = 509)		
	Knowing the new term for epilepsy		
	OR	95% CI	p value
Independent variables			
Knowledge about epilepsy score 4–5[a]	1.599	0.755–3.390	0.220
Knowledge about epilepsy score 6–7[a]	4.601	1.917–11.046	0.001
Adjusted variables of family members			
Age, years	1.027	0.984–1.072	0.228
Gender, female	2.042	1.077–3.872	0.029
Education, high school[b]	1.352	0.527–3.466	0.530
Education, university[b]	3.004	1.107–8.150	0.031
Sibling or offspring[c]	1.786	0.403–7.915	0.445
Spouse[c]	2.736	0.764–9.800	0.122
Adjusted variables of patients			
Age 20–39 years[d]	0.869	0.247–3.060	0.827
Age ≤ 19 years[d]	0.499	0.070–3.546	0.487
Age at seizure onset, years	0.933	0.885–0.983	0.010
Duration of epilepsy, years	0.908	0.855–0.3965	0.002

CI, confidence interval; OR, odds ratio.

The range of possible scores of the knowledge about epilepsy, 0–7.

[a] Reference: knowledge about epilepsy, score 0–3.
[b] Reference: education, middle school.
[c] Reference: relation to patient, parents.
[d] Reference: age ≥ 40 years.

Table 5

Comparisons between the questionnaires using the new and old terms of epilepsy in participants who knew the new Korean term for epilepsy.

	Adult patient groups	
	Types of questionnaires	
	New term (n = 142)	Old term (n = 88)
Gender, female, n (%)	67 (48.9)	36 (41.4)
Age, years, mean (SD)	34.2 (11.7)*	37.5 (12.0)
Education, n (%)		
Middle school	7 (5.1)	1 (1.2)
High school	35 (25.4)	30 (34.9)
University	96 (69.6)	55 (64.0)
Stigma Scale-Revised, n (%)		
Score = 0	53 (37.3)	26 (29.5)
Score 1–3	62 (43.7)	45 (43.7)
Score ≥4	27 (19.0)	17 (19.3)
Disclosure Management Scale, n (%)		
Score 0–3	25 (17.6)	16 (18.2)
Score 4–6	50 (35.2)	31 (35.2)
Score ≥7	67 (47.2)	41 (46.6)
PHQ-9 score ≥10, n (%)	31 (22.1)	14 (15.9)
Knowledge about epilepsy, n (%)		
Low (score 0–3)	25 (17.6)	15 (17.0)
Middle (score 4–5)	64 (45.1)	34 (38.6)
High (score 6–7)	53 (37.3)	39 (44.3)

PHQ-9, Patient Health Questionnaire-9; SD, standard deviation.

The range of possible scores of the measures: knowledge about epilepsy, 0–7; Stigma Scale-Revised, 0–9; Disclosure Management Scale, 0–12; and PHQ-9, 0–27.

* p < 0.05.

needed to determine the effects of renaming epilepsy on reducing negative public attitudes toward epilepsy.

Declaration of competing interest

We declare no conflicts of interest in relation to this study.

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