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ORIGINAL ARTICLE

Self-stigma among people with epilepsy: Comparison between Germany and Japan

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Abstract

Objective: Epilepsy is a neurological disorder characterized by recurrent seizures, with prevalence and treatment availability varying across countries. Stigma associated with epilepsy significantly impacts the quality of life (QOL) of people with epilepsy (PWE). This study aimed to compare self-stigma, depressive symptoms, anxiety, and QOL in PWE treated at tertiary epilepsy centers in Germany and Japan. It also explored cultural differences influencing these experiences.

Methods: Participants were recruited from the Bethel Epilepsy Center in Germany and the Comprehensive Epilepsy Centers at Saitama Medical University in Japan. Eligible participants were PWE aged 18 and above, receiving treatment at these facilities, meeting language requirements, and capable of providing informed consent. Data collection occurred from May 2022 to April 2023 using questionnaires assessing self-stigma (Epilepsy Self-Stigma Scale, ESSS), self-esteem, depressive symptoms, anxiety, knowledge, and QOL. Comparisons between Japanese and German samples and associations among variables were analyzed using t-tests, chi-square tests, and regression analyses.

Results: PWE in Japan reported higher levels of self-stigma, depressive symptoms, and anxiety compared to those in Germany. Conversely, they demonstrated lower epilepsy knowledge, self-esteem, and overall health. Significant correlations emerged among variables; however, differences in ESSS scores remained significant in a multiple regression model, highlighting persistent cultural variances.

Significance: The findings reveal marked differences in self-stigma and psychosocial factors between Japanese and German PWE. Japanese participants experienced higher self-stigma and psychological distress, potentially due to disparities in healthcare delivery systems, institutional frameworks, and social support structures. Healthcare providers should address these contextual factors

in epilepsy care. Future studies should explore systemic influences on self-stigma through long-term, multi-center research in diverse healthcare settings to improve support for PWE globally.

Plain Language Summary: This study compared how people with epilepsy treated in two tertiary epilepsy centers in Japan and Germany feel about their condition and themselves. The research found that Japanese patients felt more stigma (negative self-judgment) about having epilepsy and reported more feelings of depression and anxiety than German patients. They also knew less about epilepsy and felt less confident about themselves. These findings suggest that differences in healthcare systems and social attitudes between the two countries may affect how people cope with epilepsy, highlighting the need for better support systems in Japan.

KEYWORDS

anxiety, depressive symptoms, people with epilepsy, self-esteem

1 | INTRODUCTION

Epilepsy is a frequent neurological condition characterized by the occurrence of repeated unprovoked epileptic seizures.[1] The point prevalence of active epilepsy is 6.38 per 1000 persons, while the lifetime prevalence is 7.60 per 1000 persons in the world.[2] Meinardi et al. (2001) emphasized the disparities in the treatment of epilepsy due to differences in country-specific backgrounds and levels of development in the International League Against Epilepsy (ILAE) Commission Report the Treatment Gap in Epilepsy.[3] For Asian countries, Mac et al. (2007) concluded that especially economic factors influence the availability of epilepsy treatment. Furthermore, beyond the treatment gap, the presence of negative social attitudes toward epilepsy constitutes a distinctive feature within the Asian context.[4] Unfortunately, people with epilepsy (PWE), along with their families, may encounter instances of prejudice and discrimination stemming from traditional health beliefs and misconceptions surrounding the condition.[5] The prevalence of discrimination toward PWE is observed in some regions, particularly non-Western populations.[6] Lim et al. (2011) found in a systematic review that there were differences in attitudes toward epilepsy between Western and non-Western populations, with Asian and African populations having more negative attitudes than those in Australia and the Americas.[7] The World Health Organization approved the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031, it has the goal of reducing or removing structural barriers that affect PWE and their families.[8,9] As exemplified by research conducted in Japan, PWE frequently is facing challenges in establishing marital relationships, securing work opportunities, and engaging in social interactions as a result of their medical condition.[10] Notwithstanding certain advancements in changing societal perspectives on epilepsy, a considerable proportion of people continue to experience feelings of insecurity or discomfort when interacting with PWE. The phenomenon of unfavorable beliefs and attitudes, referred to as "stigma," poses significant challenges for those who are affected by epilepsy and other neurological conditions.

In this study, we define culture as the shared beliefs, practices, norms, and values that shape individual and group behaviors within a society. Understanding

Key points

- We compared self-stigma and related aspects of people with epilepsy (PWE) between Japanese and German samples.
- PWE in Japan reported higher levels of self-stigma and lower knowledge of epilepsy than those in Germany.
- Lower epilepsy knowledge and self-esteem in Japanese participants suggest the need for enhanced support.
- Healthcare systems, institutional factors, and societal factors significantly probably impact patient experiences of stigma.

cultural differences is essential, as cultural values and norms influence perceptions of epilepsy and stigma differently across countries. This study focuses on the cultural context as a key framework for analyzing self-stigma in epilepsy.

Previous studies have documented the psychosocial challenges of PWE. For example, Dodrill et al. (1984) found that emotional adjustment was the most significant challenge for PWE in Western countries, surpassing the difficulties of seizure management.[11] Similarly, Buck et al. (1999) found significant variations among countries concerning quality of life (QOL), its impact on daily living, and perceived stigma among PWE. The study encompassed several Western countries, for example, Spain, the Netherlands, France, Italy, Germany, the United States, Canada, and the United Kingdom.[12] The authors postulated that these differences stem from social and political institutional variations and change over time. Negative attitudes toward epilepsy, that is, social distance and negative stereotypes, have continuously decreased in Germany over the past 50 years and are now comparable to European countries with lower levels of negative attitudes.[13]

Further comparative studies have investigated the awareness and understanding of epilepsy. An analysis involving 6156 individuals with epilepsy (PWE) from 10 European countries found significant differences between countries regarding knowledge about epilepsy medications and causes.[14] The examination of public knowledge on epilepsy has revealed a more widespread occurrence of misinformation in Asia and Africa compared to Western nations.[15] These misconceptions contribute to heightened stigma and diminished quality of life for PWE, thus underscoring the global necessity for accurate dissemination of information.[16]

Stigma exhibits considerable variation across countries, with its manifestation being more profoundly influenced by the label of epilepsy than by the frequency or type of seizures.[17] The ILAE Task Force on Stigma in Epilepsy found that internalizing stigma about epilepsy is associated with a lower quality of life and increased risk of mental health problems, emphasizing the importance of investigating mechanisms of stigma formation in a cultural context using established measurement scales.[18] A systematic review of qualitative studies has also highlighted the profound impact of internalized, or 'self-stigma,' on PWE's lives.[19] However, the current state of international comparative research reveals a notable deficiency in addressing self-stigma specifically.

In a previous study, we developed and validated an empirical scale to measure self-stigma in Japanese, namely the Epilepsy Self-Stigma Scale (ESSS).[20] We crafted this scale by conducting semi-structured interviews with PWE, aiming to reflect the perspectives of the people concerned as comprehensively as possible. We also developed a German version (ESSS-G).[21]

The aim of this study was to compare self-stigma between German and Japanese PWE treated in two large tertiary epilepsy centers. This study, derived from data gathered at two facilities—Bethel Epilepsy Center in Germany and Saitama Medical University in Japan—constitutes the inaugural cross-cultural comparison of self-stigma in PWE between these nations. We further evaluated and contrasted additional dimensions potentially associated with self-stigma, specifically self-esteem, depressive symptoms, anxiety, epilepsy-specific knowledge, and general quality of life and health.

2 | METHODS

2.1 | Participants and procedure

From May to October 2022, we collected questionnaire data in Germany at the Bethel Epilepsy Center (Krankenhaus Mara), the University Hospital for Epileptology in Bielefeld, Germany. These data have been used to validate the German version of the ESSS.[21] From February to April 2023, we collected data from PWE at the Department of Psychiatry (Comprehensive Epilepsy Center), Saitama Medical University Hospital and Department of Psychiatry (Epilepsy Clinic) Saitama Medical Center, Saitama Medical University in Saitama, Japan.

Eligibility criteria for both centers were age 18 years or older, a confirmed diagnosis of epilepsy through electroencephalogram and other diagnostic examinations, fluency in German or Japanese, and ability to understand the respective questionnaires. Participants were recruited by direct invitation from their physician or research assistant specializing in psychology, neurology, or psychiatry. We excluded persons with intellectual disability, severe mental illness, language impairment, and inability to grant voluntary consent. The Institutional Review Boards of the University of Münster, Germany (No. 2022-050-f-S), Saitama Medical Center, Japan (No. 2021-106), and Saitama Medical University Hospital, Japan (No. 2022-064) approved the study, with assured confidentiality during data collection.

2.2 | Measures

2.2.1 | The Epilepsy Self-Stigma Scale (ESSS)

The Japanese-developed ESSS is an 8-item, self-administered questionnaire measuring the internalized stigma suffered by PWE.[10,20] The ESSS items are answered on a 4-point Likert scale: 1: Strongly Disagree, 2: Slightly Agree, 3: Agree, 4:

Strongly Agree. Total scores range from 8 to 32. Higher scores indicate greater self-stigma caused by epilepsy. For the Japanese ESSS, an exploratory factor analysis showed three factors: internalizing stigma, societal incomprehension, and confidentiality. Cronbach's α for all items and each factor demonstrated acceptable internal consistency (Cronbach's $\alpha = 0.76–0.87$). The reliability and validity of the German version of ESSS (ESSS-G) have also been demonstrated.[21] The ESSS-G has a unifactorial structure and high reliability (Cronbach's $\alpha = 0.80$). For the present study, we utilized solely the total score of the ESSS in the Japanese data to make it comparable to the German data.

2.2.2 | Rosenberg Self-Esteem Scale (RSES)

We measured self-esteem using the Japanese[19,22] and German[20,23] versions of the Rosenberg Self-Esteem Scale (RSES), which has 10 Likert-scaled items (0: strongly disagree to 3: strongly agree), with higher scores indicating higher self-esteem.

2.2.3 | Neurological Disorders Depression Inventory for Epilepsy (NDDI-E)

We assessed depressive symptoms using the Japanese[24] and German[25] versions of the NDDI-E (Neurological Disorders Depression Inventory for Epilepsy), consisting of six items answered on a 4-point Likert scale (1: Never to 4: Always or often), with higher scores indicating more recent depressive symptoms distinct from medication side effects or cognitive impairment.[26]

2.2.4 | Generalized Anxiety Disorder 7 (GAD-7)

Anxiety symptoms were assessed using the Japanese[27] and German[28] versions of the GAD-7, which has seven Likert-scaled items (0: Not at all to 3: Nearly every day), with higher scores on this scale indicating higher levels of anxiety. This scale measured initial symptoms over the past 2 weeks related to tension, restlessness, and worry typical of generalized anxiety disorder (GAD) but has also been found helpful in PWE.[29,30]

2.2.5 | Epilepsy Knowledge Scale

To evaluate patients' epilepsy knowledge, we utilized the 18-item Epilepsy Knowledge Scale (EKS), initially developed for the MOSES educational program in Germany.[31] An adapted version for Japan,[32] excluding an item on driving due to variations in road traffic laws, has been extensively used in Japan.[33–35] Patient responses were scored from 0 to 100 based on the percentage of correct answers, with higher scores indicative of a more comprehensive understanding of epilepsy.

2.2.6 | Overall QOL and health

To evaluate overall quality of life and general health, we used the Japanese[36] and German[37] versions of two items of the Quality of Life in Epilepsy Questionnaire (QOLIE-31). We assessed the overall QOL on a scale ranging from 0 (indicating the worst possible QOL, as bad as or worse than being dead) to 10 (representing the best possible QOL). Similarly, overall health was evaluated on a scale from 0 (representing the worst imaginable health state) to 100 (indicating the best imaginable health state).

2.3 | Demographic and epilepsy-related variables

We also asked participants in the questionnaire for the following information: age, gender, living situation, employment status, age at first seizure, and seizure frequency. In addition, we collected information such as diagnosis of epilepsy, seizure type, comorbid psychiatric disorders, and medication data, including antiseizure medications (ASMs), psychotropic medications, and benzodiazepines from medical records.

2.4 | Statistical analyses

The collected data were pooled separately between Japanese and German samples. First, we calculated descriptive statistics for the demographic variables, epilepsy-related variables and each scale. We examined the differences between Japanese and German samples for each variable by *t*-test or Fisher's exact test. The effect size was computed and interpreted according to established benchmarks: Cohen's *d* was adopted to assess mean differences, with thresholds defined as small (0.20–0.49), medium (0.50–0.79), and large (≥0.80).[38] Cramer's *V* was employed to evaluate the strength of associations between sample and categorical variables, with effect sizes categorized as small (0.20–0.49), medium (0.50–0.79), and large (≥0.80).[39]

Second, we conducted correlation analyses to examine the associations between the scales, and with demographic

and epilepsy-related variables separate for Japanese and German samples. We used Pearson correlations or point-biserial correlations and compared them between the Japanese and German samples.

In the third step, we used linear regression analysis to find significant predictors of the study participants' ESSS scores. Based on the variables with significant correlations with the ESSS in one or both samples, we included all predictors that were significant in simple regression models in a multiple regression model. We used backward selection to exclude nonsignificant predictors.

For statistical analyses, we utilized IBM SPSS for Windows (version 29) and R (package "cocor"). The threshold for statistical significance was set at $\alpha = 0.05$. In comparing frequencies between Japanese and German samples, a significant difference was denoted by an absolute value of the adjusted standardized residual exceeding 1.96.

3 | RESULTS

3.1 | Descriptive statistics and comparison between Japanese and German samples

In Germany, 128 out of 146 patients who had been asked to participate gave informed consent and completed the study questionnaire. The response rate was 87.7%, and 115 cases were analyzed (excluding 11 patients with no epilepsy diagnosis and 2 patients under 18 years old).

In Japan, 106 of 129 patients who met the inclusion criteria agreed to participate. The response rate was 82.3%, and 104 patients were analyzed (excluding two patients younger than 18).

Table 1 presents the descriptive statistics and the comparison between Japanese and German samples.

When the demographic variables (i.e., age, gender living situation, employment status) were compared, the analysis showed significant differences only in living situation, with more PWE living alone in Germany than in Japan ($p = 0.003$, $V = 0.20$). Furthermore, while in Japan only outpatients were recruited for study participation, there was an approximately equal split between outpatients and inpatients in Germany ($p < 0.001$, $V = 0.57$). However, an additional analysis comparing outpatients and inpatients in Germany revealed that the only significant difference was in living style, with a smaller proportion of outpatients living alone ($p = 0.027$, $V = 0.22$).

We then examined epilepsy-related variables. Concerning seizure frequency, Japan had more patients with no self-reported seizures in the last 6 months, whereas Germany had more patients with weekly seizures ($p < 0.001$, $V = 0.31$). We also identified a notable difference in the number of medications, with Japan having higher rates of ASMs ($p = 0.003$, $d = 0.41$), psychotropic medication ($p < 0.001$, $V = 0.24$), and benzodiazepines ($p < 0.001$, $V = 0.41$). However, when benzodiazepines were excluded from the analysis of the number of ASMs, the difference between the Japanese and German samples was no longer significant ($p = 0.289$, $d = 0.14$). In addition, Japan had higher rates of psychiatric comorbidities ($p < 0.001$, $V = 0.26$). In the supplementary analysis comparing outpatient and inpatient ESSS in Germany, no significant differences were found ($p = 0.907$).

3.2 | Comparison of outcome scales between Japanese and German PWE

Next, we compared outcome measures, including self-stigma, between Japanese and German PWE (Table 2). The comparison of self-stigma assessed with the ESSS showed significantly higher scores for Japanese than for German PWE with a medium effect size ($p < 0.001$, $d = 0.63$). Regarding other outcome measures, patients from Japan had significantly lower self-esteem (RSES, $p < 0.001$, $d = 1.38$), knowledge about epilepsy (EKS, $p < .001$, $d = 1.55$), overall QOL ($p = 0.002$, $d = 0.43$), and overall health ($p = 0.008$, $d = 0.36$) compared to German patients. Conversely, Japanese PWE reported higher levels of depressive symptoms (NDDI-E, $p = 0.008$, $d = 0.36$), but no difference was found for GAD-7 ($p = 0.772$).

3.3 | Correlations between ESSS and other variables

Table 3 displays the results of the correlation analysis between the ESSS scores and other variables.

In the Japanese sample, there was no significant correlation between ESSS scores and age, being employed, or age at first seizure. Conversely, in the German sample, weak but significant negative correlations were observed between ESSS scores and age ($r = -0.21$, $p < 0.05$), being employed ($r = -0.21$, $p < 0.05$) and age at first seizure ($r = -0.27$, $p < 0.01$). The comparison of the correlations between the samples revealed that only the correlation between ESSS and age was significantly different ($z = 2.24$, $p = 0.025$). In both the Japanese and the German sample, the ESSS correlated significantly with gender (both $r = 0.25$, $p < 0.01$), indicating that female patients reported higher ESSS scores.

Regarding outcome measures, in the Japanese PWE, there were weak negative correlations between ESSS and both overall QOL ($r = -0.21$, $p < 0.05$) and overall health ($r = -0.25$, $p < 0.05$), a moderate negative correlation with RSES ($r = -0.41$, $p < 0.001$), and positive correlations with

TABLE 1 Comparison of Japanese and German people with epilepsy (PWE): Demographic and epilepsy-related variables.

	Japan ($n=104$)		Germany ($n=115$)		p	d (V)
Age (years), M/SD	41.3	16.3	37.7	16.9	0.117	0.21
Range	18—77		18—80			
Gender, female (n/%)†	62	59.6	61	53.0	0.343	0.07
Outpatient (n/%)†	104	100	57	49.6	<0.001	0.57
Living style, alone (n/%)†	9	8.7	27	23.5	0.003	0.20
Employment status, employed (n/%)†	54	51.9	55	47.8	0.589	0.04
Age at first seizure (years), M/SD	22.2	15.7	23.0	16.4	0.712	0.05
Range	0–69		0–69			
Epilepsy†						
Focal (n/%)	68	65.4	78	67.8	0.419	0.09
Generalized (n/%)	16	15.4	22	19.1		
Unkown/other (n/%)	20	19.2	15	13.0		
Seizure frequency†						
No seizures in the last 6 months	59	56.7	37	32.2	<0.001	0.31
1–2 seizures in the last 6 months	15	14.4	24	20.9		
3–5 seizures in the last 6 months	11	10.6	13	11.3		
At least once a month	13	12.5	15	13.0		
At least once a week	2	1.9	19	16.5		
At least once a day	4	3.8	7	6.1		
Psychiatric comorbidities, with (n/%)†	27	26.0	8	7.0	<0.001	0.26
ASMs	2.1	1.1	1.70	0.9	0.003	0.41
ASMs (excluding benzodiazepines)	1.8	0.9	1.7	0.8	0.289	0.14
Psychotropic drugs (n/%)†	24	23.1	7	6.1	<0.001	0.24
Benzodiazepines (n/%)†	37	35.6	4	3.5	<0.001	0.41

Note: Items marked with a dagger symbol (†) represent Fisher's exact tests, and Cramer's V values instead of Cohen's d values. Additionally, items that showed significant differences in the residual analysis are highlighted in bold.

Abbreviations: ASMs, antiseizure medications; EKS, Epilepsy Knowledge Scale; SD, standard deviation.

TABLE 2 Comparison of Japanese and German PWE: Outcome scales.

	Japan ($n=104$)		Germany ($n=115$)			
	M	SD	M	SD	p	d
ESSS	19.1	5.7	15.8	4.9	<0.001	0.63
Overall QOL	6.0	2.5	7.0	2.1	0.002	0.43
Overall Health	60.5	22.3	68.0	19.1	0.008	0.36
RSES	14.5	6.6	22.6	5.1	<0.001	1.38
NDDI-E	12.7	4.8	11.1	3.8	0.008	0.36
GAD-7	6.3	5.7	6.1	4.9	0.772	0.04
EKS	34.7	12.7	60.5	19.5	<0.001	1.55

Abbreviations: EKS, Epilepsy Knowledge Scale; ESSS, Epilepsy Self-Stigma Scale; GAD-7, Generalized Anxiety Disorder-7; NDDI-E, Neurological Disorders Depression Inventory for Epilepsy; RSES, Rosenberg Self-Esteem Scale; SD, standard deviation.

TABLE 3 Correlation Analysis of Japanese and German PWE.

	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)
1) ESSS		**0.09**	0.25**	−0.01	−0.12	−0.21*	−0.25*	−0.41***	0.49***	0.44***
2) Age	**−0.21***		0.04	−0.13	0.59***	0.00	−0.01	0.20*	−0.07	−0.02
3) Gender (female)	0.25**	−0.19*		−0.09	−0.16	−0.08	−0.07	−0.18	0.21*	0.27**
4) Employed	−0.21*	0.01	−0.04		0.06	0.10	0.06	0.12	−0.17	−0.04
5) Age at first seizure	−0.27**	0.55***	−0.15	0.05		0.12	0.14	0.22*	−0.13	−0.08
6) Overall QOL	−0.40***	−0.04	−0.06	0.11	−0.05		0.71***	0.61***	−0.54***	−0.44***
7) Overall health	−0.35***	−0.05	−0.04	0.14	−0.04	0.81***		0.53***	−0.52***	−0.47***
8) RSES	−0.41***	−0.03	−0.10	0.14	0.04	0.52***	0.44***		−0.64***	−0.56***
9) NDDI-E	0.45***	−0.05	0.20*	−0.05	−0.13	−0.50***	−0.47***	−0.50***		**0.76*****
10) GAD-7	0.54***	−0.19*	0.25**	−0.10	−0.08	−0.58***	−0.57***	−0.47***	**0.60*****	

Note: Upper right values are for Japan; lower left values are for Germany. Correlations with significant differences between the Japanese and German samples are shown in bold. Only variables with a significant correlation with ESSS in at least one of the samples are shown. No significant correlations with ESSS were found for the following variables: living alone, seizure frequency, psychiatric comorbidity, Epilepsy Knowledge Scale.

Abbreviations: ESSS, Epilepsy Self-Stigma Scale; GAD-7, Generalized Anxiety Disorder-7; NDDI-E, Neurological Disorders Depression Inventory for Epilepsy; QOL, quality of life; RSES, Rosenberg Self-Esteem Scale.

*$p<0.05$. **$p<0.01$. ***$p<0.001$.

NDDI-E ($r=0.49$, $p<0.001$) and GAD-7 ($r=0.44$, $p<0.001$). In the German PWE, moderate negative correlations were observed between ESSS and both overall QOL ($r=-0.40$, $p<0.001$) and overall health ($r=-0.35$, $p<0.001$), a negative correlation with RSES ($r=-0.41$, $p<0.001$), and positive correlations with NDDI-E ($r=0.45$, $p<0.001$) and GAD-7 ($r=0.54$, $p<0.001$). The correlations were not significantly different between the Japanese and German samples.

In both samples, the correlations of the ESSS with living alone, seizure frequency, psychiatric comorbidity, and the EKS were not significant. In the Japanese PWE, EKS was not significantly correlated with any of the variables, whereas in the German PWE, there was a weak positive correlation with overall health ($r=0.23$, $p<0.05$).

3.4 | Regression analysis

Table 4 shows the results of linear regression analyses for the prediction of the study participants' ESSS scores.

The unstandardized regression coefficient from the simple regression model for the study sample (Japanese vs. German PWE, $b=-3.30$, $p<0.001$) corresponds to the mean difference reported in Table 2. Other significant predictors of ESSS in simple regression models were gender, age at first seizure, overall QOL and health, RSES, NDDI-E and GAD-7 (all $p<0.01$, Table 4). The final model from multiple regression still shows a significant difference in ESSS scores between the Japanese and German samples ($b=-1.78$, $p=0.022$), with other independent predictors being age at first seizure, RSES, NDDI-E and GAD-7 (Table 4). These variables explained 36% of the criterion variance ($R^2=0.36$, $p<0.001$).

4 | DISCUSSION

4.1 | Differences in patient characteristics and comparison of outcome variables of Japanese and German PWE

Our comparison of Japanese and German samples of PWE evinced that Japanese patients had higher levels of self-stigma, depressive symptoms, and anxiety compared to German patients despite achieving more solid self-reported seizure control in the past 6 months. In addition, knowledge of epilepsy, self-esteem, QOL, and subjective health degree were also lower in Japanese PWE. Prior studies have established a link between frequent seizures and increased stigma surrounding epilepsy.[40,41] In addition, a systematic review of serious mental illness and self-stigma by Dubreucq et al. shows that increased transition to psychosis and poor clinical and functional outcomes are both associated with self-stigma.[42] The high prevalence of psychiatric comorbidities and the number of prescriptions of psychotropic and benzodiazepine medications in Japan suggest that mental health problems, considered to require treatment rather than epilepsy itself, contribute to higher self-stigma. The higher prevalence of psychiatric comorbidities among Japanese PWE and the higher number of prescriptions for

TABLE 4 Linear regression analysis for the prediction of ESSS scores.

	Simple regression models			Multiple regression model		
	b (SE)[a]	*β*[b]	*p*	*b* (SE)	*β*	*p*
Intercept	–	–	–	17.47 (1.90)		<0.001
Sample: German PWE	−3.30 (0.71)	−0.30	<0.001	−1.78 (0.77)	−0.16	0.022
Age	−0.01 (0.02)	−0.02	0.745			
Gender: female	2.85 (0.73)	0.26	<0.001			
Employed	−0.98 (0.74)	−0.09	0.188			
Age at first seizure	−0.06 (0.02)	−0.19	0.005	−0.04 (0.02)	−0.12	0.030
Overall QOL	−0.80 (0.15)	−0.34	<0.001			
Overall health	−0.09 (0.02)	−0.33	<0.001			
RSES	−0.38 (0.04)	−0.49	<0.001	−0.13 (0.06)	−0.17	0.041
NDDI-E	0.63 (0.07)	0.50	<0.001	0.23 (0.10)	0.18	0.032
GAD-7	0.49 (0.06)	0.47	<0.001	0.27 (0.08)	0.26	0.001

Note: The multiple regression model included all predictors with significant effects in the simple regression models and backward selection was used to exclude nonsignificant predictors. Final model: $R^2 = 0.36$, $p < 0.001$.

Abbreviations: ESSS, Epilepsy Self-Stigma Scale; GAD-7, Generalized Anxiety Disorder-7; NDDI-E, Neurological Disorders Depression Inventory for Epilepsy; PWE, people with epilepsy; QOL, quality of life; RSES, Rosenberg Self-Esteem Scale.

[a]Unstandardized regression coefficients with standard errors.

[b]Standardized regression coefficients.

psychotropic drugs may have been influenced by differences in the departments that provide epilepsy care. In this study, the PWE in Germany was seen by a neurologist, whereas for PWE in Japan, the primary physician was a psychiatrist. While Lopez et al. (2019) noted a lack of psychiatric involvement in epilepsy care in the United States,[43] on the contrary, psychiatrists used to play a central role in treating seizure and psychiatric symptoms from the beginning of epilepsy practice in Japan.[44] The difference in the complication rate of psychiatric comorbidities between Japanese and German samples in our study may be influenced by the specialty of the attending physician.

4.2 | Differences in self-stigma between Japanese and German samples: Possible explanations

The differences in self-stigma between Japanese and German participants can be understood through both societal and individual-level factors. Contemporary anthropological perspectives suggest that health experiences, including stigma, are shaped by complex interactions between social structures, cultural practices, and healthcare systems.[45] In this study, we conceptualize culture as the shared beliefs, norms, values, and practices that shape individual and collective behavior within a society. This perspective allows us to distinguish cultural factors from societal factors (e.g., healthcare systems, legal frameworks) and psychosocial aspects (e.g., individual psychological responses). The findings indicate that cultural differences significantly influence self-stigma. For example, Japan's collectivist cultural orientation emphasizes social harmony and conformity, which may heighten sensitivity to societal judgments and amplify internalized stigma. Conversely, Germany's individualistic cultural orientation, combined with stronger legal protections for individuals with disabilities, may reduce the perceived need for concealment and mitigate stigma's impact. These cultural dynamics illustrate how broader cultural values can shape individual experiences of stigma and self-perception. In Japan, research has shown that social relationships and community belonging play crucial roles in shaping individual health experiences and identity.[46] In a comparative study involving 22 cultures on mental illness stigma, findings indicated that the correlation between experienced and perceived stigma and self-stigma was more significant in culture characterized by a higher degree of collectivism.[47]

At the micro level, PWE frequently resorts to concealment as a strategy to mitigate prejudice, leading to a more confined community and diminished quality of life.[18] In Japan, particularly when seizure frequency is high, concerns about social judgment and subsequent concealment

can result in community disconnection. This social withdrawal may contribute to depression, lowered self-esteem, and the development of self-stigma.

On the contrary, Germany's more developed legal protections for PWE (e.g., book IX of the German Social Code: Rehabilitation and participation of people with disabilities) and fewer daily life barriers may reduce the need for concealment, especially in public settings like employment. Consequently, German PWE's self-stigma appears to stem more from individual interpersonal anxiety, with fewer instances of shame compared to their Japanese counterparts.

Furthermore, previous studies determined that incorrect knowledge and misconceptions create negative attitudes toward patients, increasing stigma.[48,49] However, neither the Japanese survey nor the present study found a correlation between knowledge about epilepsy and self-stigma[34] since self-stigma is an internalized stigma within the patients and is a complex phenomenon. The community's knowledge is vital in social stigma (experienced by PWE),[16,40] which may influence their self-stigma. However, it may be challenging to reduce the patient's self-stigma solely by acquiring correct (personal) knowledge about epilepsy. Individuals understanding health and self-care information has been shown to improve cognitive and social skills and enable people to act appropriately in health-related situations.[35] Attaining precise knowledge about epilepsy and cultivating positive life experiences that leverage such knowledge, subsequently contributing to sustained elevated self-esteem throughout an individual's life, may serve as a valuable strategy in alleviating self-stigma.

4.3 | Limitations

This study sought to conduct an international comparison of self-stigma between Japanese and German samples of PWE. Nevertheless, its scope was constrained by including only a limited number of facilities in each country. The German participants were from the Bethel Epilepsy Center, a large tertiary epilepsy center treating many patients with difficult-to-treat epilepsies, which might explain the higher seizure frequencies in the German sample. Conversely, the Japanese survey in the department of outpatient psychiatry (comprehensive epilepsy center and epilepsy clinic) at the university hospital likely included more patients with complex psychiatric symptoms. Both facilities are tertiary referral centers for epilepsy. Therefore, both groups of PWE might differ from PWE who are treated in a general hospital without an epilepsy center or by a general neurologist. Future studies should involve more centers in each country for broader representation.

The cross-sectional nature of our study precluded establishing causal relationships that lead to the formation of self-stigma. Future longitudinal studies are needed to investigate causality. In addition, while this study distinguishes culture from societal and psychosocial aspects, it does not capture the full complexity of cultural influences, such as variations within each country or intersections with other demographic factors (e.g., age, gender). Future studies should include more nuanced cultural measures and investigate their interactions with societal and individual-level variables to better understand their combined effects on self-stigma.

Furthermore, since this study relied on variables related to individual characteristics and states, such as self-esteem and anxiety, future research should incorporate specific variables that measure the context of "interpersonal" relationships, and a more comprehensive understanding of self-stigma formation is needed.

Finally, the NDDI-E was developed and validated to screen for major depression in PWE and was not specifically designed to measure the severity of depression on a continuous scale. However, the validation studies reported a high correlation between the NDDI-E scale score and the Beck Depression Inventory, which assesses symptom severity (Gilliam et al., 2006; Brandt et al., 2014). An advantage of the NDDI-E is its brevity, but it has to be kept in mind that its scale score has not been specifically validated as a measure of depression severity.

5 | CONCLUSIONS

Our study found that PWE treated in a tertiary epilepsy center in Japan report higher levels of self-stigma than those in Germany. Healthcare providers should incorporate the cultural context into their treatment and intervention strategies. Additionally, a more in-depth investigation is necessary to comprehend these subtle differences, their potential impact on patient care, and the development of supportive approaches. Future studies should aim to expand the scope of research by including diverse populations and settings to enhance the generalizability of the findings.

AUTHOR CONTRIBUTIONS

IK, AH, and CB designed the study; IK, HO, and SW collected the data; IT and AH analyzed the data; CB, KM, HY, and CGB were involved in the study design. They also reviewed the manuscript. All authors contributed to the paper and approved the submitted version.

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CONFLICT OF INTEREST STATEMENT

Author CB has received support from, and/or has served as a paid consultant for Angelini/Arvelle, Eisai, GW/Jazz Pharmaceuticals, Johnson&Johnson, Marinus, UCB Pharma, Xenon und Zogenix. The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article have been archived by the authors. Due to confidentiality obligations, the data will not be made available to the general public, but anonymized data will be provided upon reasonable request.

ETHICS STATEMENT

This study was conducted following the approval of the study protocol by the institutional review board of Munster University in Germany (approval No. 2022-050-f-S), the institutional review board of Saitama Medical Center, Saitama Medical University in Japan (approval No. 2021-106), and Saitama Medical University Hospital, Saitama Medical University in Japan (No. 2022-064). Participation was voluntary, and information was collected anonymously after obtaining written consent from each respondent. Participants were assured that their data would be kept confidential throughout the data collection period.

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