A study of factors influencing self-stigma in people with epilepsy: A nationwide online questionnaire survey in Japan

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Abstract

Objective: Epilepsy carries a significant stigma. While there is some evidence that self-stigma accompanies a lack of knowledge about epilepsy, there are no studies in Japan. This study aimed to determine factors contributing to self-stigma in Japan.

Methods: We conducted an online questionnaire survey. Three hundred and ten patients completed the questionnaire (mean age of 47.8 ± 11.9) in contrast to the total registered users on the questionnaire site as 28,315 from Jul 29 to Aug 2, 2021. We asked about demographic variables, satisfaction with treatment, limitations in life, support status, seizure frequency, the Epilepsy Self-Stigma Scale (ESSS), the Rosenberg Self-Esteem Scale (RSES), and the Epilepsy Knowledge Scale (EKS). We conducted the statistical analysis on self-stigma, self-esteem, knowledge of epilepsy, and seizure frequency associations by Spearman’s rank correlation.

Results: The mean value of the EKS was 40.19 ± 18.75, the ESSS was 17.69 ± 6.25, and the RSES was 26.02 ± 6.13. We identified a significant moderate negative correlation between self-esteem and self-stigma (P < .001, ρ = −.423), a significant weak positive correlation between self-esteem and knowledge (P = .005, ρ = .177), and a significant weak negative correlation between seizure frequency and self-stigma (P < .001, ρ = −.162). Of the 186 respondents who were working or studying, 91 (49%) participants had experienced any discrimination due to epilepsy. The use of psychosocial support, that is, participating in epilepsy self-help groups and educational programs, was 5.8%.

Significance: There was no correlation between the strength of self-stigma and the knowledge, while there was a positive correlation between self-esteem and knowledge (P = .005, ρ = .177). There was a negative and weak correlation between seizure frequency and self-stigma (p < .001, ρ = −.162). These results...
The stigma associated with epilepsy is prevalent in various cultures.\textsuperscript{1} It is frequently regarded as one of the most significant issues affecting the lives of patients with epilepsy (PWE) and their families.\textsuperscript{2–5} According to a report by the International League Against Epilepsy (ILAE) Task Force on Stigma in Epilepsy in 2022,\textsuperscript{6} the prevalence of stigma varies significantly by region, and factors contributing to the development of stigma include a lack of understanding of epilepsy and a lack of educational opportunities.\textsuperscript{7} Stigma accompanies a lack of information about epilepsy, low educational achievement, low socioeconomic status, undeveloped living environments (e.g., villages, etc.), and prejudices from religious (superstitious) beliefs.

Stigma perception has been linked to increased seizure frequency, younger onset age, longer duration of epilepsy, lower educational attainment, less understanding of epilepsy, and younger age.\textsuperscript{1–3} A significant result is that epilepsy terminology may contribute to stigma generation. For instance, the Japanese name for epilepsy, “tenkan,” carries the negative connotation of “kuruu” (to insane) and “a violent disposition prone to infatuation.” As a result, the name itself carries a derogatory connotation. While epilepsy is widely recognized as a disease caused by abnormal neuronal activity in the brain, stigma, and discrimination against people with epilepsy remain deeply ingrained in Japanese culture.\textsuperscript{8}

Traditionally, geographers divide Japan into eight sections/regions (Figure 1). The population is 127 million, and the capital city of Tokyo exists in the center of the largest island in Japan, with about 40 million people. The prevalence of epilepsy in Japan is about 0.8%, and about 1 million people have epilepsy. There are 37 epilepsy centers registered with the Japan Epilepsy Center Association (12 of which are in the Kanto region, Tokyo metropolitan area). While there is no significant difference in the education or medical technology levels across Japan, most universities and medical institutions are located in the Tokyo metropolitan area.
Regions and Prefectures of Japan

Hokkaido
1. Hokkaido

Tohoku
2. Aomori
3. Iwate
4. Miyagi
5. Akita
6. Yamagata
7. Fukushima

Kanto
8. Ibaraki
9. Tochigi
10. Gunma
11. Saitama
12. Chiba
13. Tokyo
14. Kanagawa

Chubu
15. Niigata
16. Toyama
17. Ishikawa
18. Fukui
19. Yamanashi
20. Nagano
21. Gifu
22. Shizuoka
23. Aichi

Kansai
24. Mie
25. Shiga
26. Kyoto
27. Osaka
28. Hyogo
29. Nara
30. Wakayama

Chugoku
31. Tottori
32. Shimane
33. Okayama
34. Hiroshima
35. Yamaguchi

Shikoku
36. Tokushima
37. Kagawa
38. Ehime
39. Kochi

Kyushu & Okinawa
40. Fukuoka
41. Saga
42. Nagasaki
43. Kumamoto
44. Oita
45. Miyazaki
46. Kagoshima
47. Okinawa

FIGURE 1  Regions and prefectures of Japan
indicate which dimensions of self-stigma are more prevalent in PWE.

In this study, we used the questionnaire developed by the authors to ascertain perceived self-stigma in Japan and to identify social and psychological elements contributing to PWE's stigmatization.

2 | METHODS

2.1 | Participants and procedure

Using an online questionnaire, we surveyed patients with epilepsy registered with an online survey service (Intage Inc.). This study collected responses from people throughout all sections of Japan. Three hundred and ten patients completed the questionnaire (mean age of 47.8 ± 11.9 years old, 190 males and 120 females) in contrast to the total registered users on the questionnaire site as 28,315 (total request numbers, including people with not epilepsy) from Jul 29, 2021, to Aug 2, 2021.

2.2 | Measures

We requested patients to answer the questionnaire, age, gender, educational history, employment status, marital status, restrictions of daily life, the condition of support, satisfaction with current support, seizure frequency in the past 6 months, seizure types (subjective by the patient, not by the name of the diagnosis), perceived worsening of seizures, and side effects of antiseizure medications, the epilepsy self-stigma scale (ESSS), the Rosenberg self-esteem scale (RSES), and the epilepsy knowledge scale.

2.2.1 | Epilepsy self-stigma scale (ESSS)

The ESSS is an eight-item scale with subscales comprising three factors: Internalization of stigma (internalized stigma), Societal incomprehension (perception of stigma), and Confidentiality (actions taken to avoid stigma). The ESSS classified into 4-point Likert-type scales: “1: Disagree”, “2: Slightly Agree”, “3: Agree”, “4: Strongly Agree.” The total score ranges from 8 to 32 points. The higher score was interpreted as a higher self-stigma caused by epilepsy. The total scale can be used to assess self-stigma in PWE. Higher scores indicate greater self-stigma caused by epilepsy. Furthermore, the subscale scores indicate which aspects of self-stigma are the most significant/relevant in PWE. Separate assessments of 1 and 2–4 response items can also be used to assess the presence or absence of patient self-stigma.

2.2.2 | Rosenberg self-esteem scale (RSES)

Self-stigma is negatively correlated to self-esteem. This study uses the RSES to assess the extent of self-esteem to examine the construct validity of the ESSS. Items are rated on a five-point Likert scale from 1 (strongly disagree) to 4 (strongly agree). Total scores range from 10 to 40. Higher scores indicate higher levels of self-esteem. We used the Japanese version of the RSES, the method identified with high validity and reliability using back translation.

2.2.3 | Epilepsy knowledge scale

To assess epilepsy-specific knowledge, we used the Epilepsy Knowledge Scale developed by Theodor W. May et al. A Japanese version of this scale (18 items) was created by Inoue et al. and back-translated and is already used in epilepsy research in Japan. This scale used three answer categories (“true,” “false,” or “I do not know”) instead of two categories since patients with epilepsy do not have to select specific answers mandatorily. This scale was created with 18 items in Japanese, but to make the evaluation easier to understand, we counted the number of questions answered correctly, and the results are expressed in terms of a 100-point scale.

2.3 | Ethical considerations

This research was implemented under the approval of the Research Ethics Committee of Saitama Medical University, Saitama Medical Center (No. 2021-106) and supported by JSPS KAKENHI Grant Number JP21K13709. Participation was voluntary and information was collected anonymously after obtaining consent from each respondent by assuring confidentiality throughout the data collection period.

2.4 | Data analysis

We conducted the statistical analysis on SPSS Ver. 25 (IBM Corp.). Descriptive data include mean, standard deviation, range, and percentage values.

We examined four types of the following associations by Spearman’s rank correlation, respectively, after confirming the normality of the data in advance:

1. The association between the Epilepsy Self-Stigma Scale and the Knowledge Scale. The significance probability was set at $P < .05$;
2. The association between the three factors of the Epilepsy Self-Stigma Scale (i.e., Internalization of stigma, Societal incomprehension, and confidentiality) and the Knowledge Scale. The significance probability was set at \( P < .05 \);
3. The association among the Rosenberg Self-Esteem Scale, the epilepsy self-stigma scale (the significance probability was set at \( P < .01 \)), and the knowledge scale (the significance probability was set at \( P < .05 \));

### RESULTS

#### 3.1 Participants’ characteristics

We received the responses to the questionnaires from 310 participants. (mean age of 47.8 ± 11.9 years, 190 males and 120 females).

Other attributes and scale scores are shown in Table 1.

#### 3.2 Correlations between self-stigma and knowledge

We used Spearman's rank correlation coefficient to examine the association between the Epilepsy Self-Stigma Scale and the Knowledge Scale after a priori checking the normality of the data. Results showed no significant correlation between the epilepsy self-stigma scale and the knowledge
In addition, we used the three factors of the Epilepsy Self-Stigma Scale (Internalization of stigma, societal incomprehension, and confidentiality) to examine the association between the three factors and knowledge after confirming the normality of the data a priori. Results showed no significant correlation between the three factors of the Epilepsy Self-Stigma Scale and the Knowledge Scale ($P = .416-.716$). We listed detailed values in Table 2.

### Table 2: Correlations between ESSS (total score and 3 factors) and EKS

| ESSS                        | EKS          |
|-----------------------------|--------------|
| $\rho$                      | $P$          |
| 1: Internalization of stigma | $−.52^{*}$   | $P = .72^{*}$ |
| 2: Societal incomprehension | $−.30^{*}$   | $P = .46^{*}$ |
| 3: Confidentiality          | $−.051^{*}$  | $P = .42^{*}$ |

*Abbreviations: EKS, Epilepsy Knowledge Scale; ESSS, Epilepsy Self-Stigma Scale.

3.3 | Correlations among self-stigma, self-esteem, and epilepsy knowledge

The association among self-esteem (RSES) and self-stigma (ESSS) and knowledge (EKS), after confirming the normality of the data a priori. The results showed a significant moderate negative correlation between self-esteem and self-stigma ($P < .001, \rho = −.423$). A significant weak positive correlation was found between self-esteem and knowledge ($P = .005, \rho = .177$). Detailed values are shown in Table 3.

### Table 3: Correlations among RSES scores and ESSS and EKS (N = 310)

| RSES          | ESSS   | EKS        |
|---------------|--------|------------|
| Spearman’s rank correlation coefficient | $−0.423^{*}$ | $0.18^{**}$ |

*Abbreviations: EKS, Epilepsy Knowledge Scale; ESSS, Epilepsy Self-Stigma Scale; RSES, Rosenberg Self-Esteem Scale.

3.4 | Correlations among seizure frequency, self-stigma, and self-esteem

The association among seizure frequency, self-stigma (ESSS), and self-esteem (RSES), after confirming the normality of the data a priori. The results showed a significant weak negative correlation between self-stigma and seizure frequency ($P < .001, \rho = −.162$). Results showed no significant correlation between seizure frequency and self-esteem ($P = .224$).

3.5 | Descriptive analysis of restrictions and difficulties due to epilepsy

We asked the participants, “How would you emotionally assess the extent of your life feeling restricted or constrained due to your ‘epilepsy’ in the last 6 months?” 98 (31.6%) of the 310 said “was not restricted at all,” 83 (26.8%) said “was limitedly restricted,” and 71 (22.9%) responded “some extent,” 37 (11.9%) responded “considerably,” and 21 (6.8%) “extremely,” respectively. The results of this question are shown in Table 4. The item that most constrained the respondents based on the result was riding a vehicle, and 18.4% said they were extremely restricted. On the contrary, the item that constrained the respondents the least was the relationship with their partners. A modest 3.9% answered that they were extremely constrained, while 70.3% of the respondents felt no constraints from epilepsy.

As for the question “if having epilepsy caused any problems in school or work,” 35 (18.8%) of the 186 patients who are in occupation or education responded “frequently,” 69 (37.1%) responded “sometimes,” and 82 (44.1%) responded “nothing.” Also, 66 (35.5%) of the people who answered said that their epilepsy kept them from doing some things at school or work, like going to the pool, working the night shift, and driving a car. In addition, when asked if the respondents had ever experienced any discrimination from their employers, coworkers, teachers, or classmates due to epilepsy, 91 (49%) participants answered they had no such experience. Twenty-nine (15.6%) participants claimed they had experienced discrimination, while 61 (19.7%) indicated they never disclosed their medical records to others.

3.6 | Descriptive analysis of desire for support for epilepsy and participation in self-help groups and educational lectures

When asked by whom they most often seek help for epilepsy in this survey, 130 respondents said doctors, 125 respondents followed parents, and 112 respondents followed their partners. Five respondents said they sought help from self-help associations, and 40 said they had no one to help with their epilepsy. Fifteen who answered “other” included searching online, visiting care services, and visiting nurses. The details are shown in Table 5.

Of the 270 respondents who reported receiving this aid, 57 (21.1%) were highly satisfied with this assistance, 98 (36.3%) were satisfied, 99 (36.7%) were fair, and 1 (36.7%)
were not highly satisfied. Eleven (4.1%) and 5 (1.9%) said they were not satisfied at all.

In our survey, when asked if they were involved in an epilepsy self-help group such as “Nami no Kai” (as the Japan Epilepsy Association), 18 (5.8%) answered yes, and 292 (94.2%) said they had never been involved. Regarding participation in educational courses and lectures on epilepsy, we also distributed this question to 18 respondents (5.8%) who participated in such events. As for specific reasons for no experience in such educational programs, the most common reason given by 36 respondents was that they did not know such programs existed in the first place. Other reasons included lack of time or money, unwillingness to reveal their health conditions to the public, resistance to attending such programs due to potential prejudice, possible damage to their self-esteem, etc.

4 | DISCUSSION

4.1 | Factors associated with self-stigma in Japanese patients with epilepsy

Our results showed a significant moderate negative correlation between self-esteem and self-stigma in patients with epilepsy ($P < .001$, $\rho = -0.423$). A significant weak positive correlation was found between self-esteem and knowledge ($P = .005$, $\rho = .177$). These results suggest that
sufficient knowledge of epilepsy may improve the self-esteem of patients with epilepsy and thus reduce the self-stigma associated with epilepsy.

Previous reports have described an association between high seizure frequency and high stigma of epilepsy. However, the results of our study showed a negative and weak correlation between seizure frequency and self-stigma ($P < .001$, $\rho = −.162$). Our results suggested that long-term life experiences are more likely to cause self-stigma than the frequency of seizures in the past 6 months. This is consistent with reports that one-fifth of seizure-free patients continue to feel stigma even after being seizure-free for more than 2 years. Improving seizure treatment status alone is not enough to reduce stigma. In our research, 91 (49%) of 186 participants had experienced discrimination from their employers, co-workers, teachers, or classmates due to epilepsy.

These results suggest that short-term epilepsy treatment for seizure control is insufficient to reduce self-stigma in patients with epilepsy. The dissemination for people to enable sufficient epilepsy knowledge and positive perceptions of epilepsy by increasing self-efficacy throughout a lifetime may reduce self-stigma.

### 4.2 Knowledge of patients with epilepsy and the potential for self-help groups and educational programs

Prospective cohort studies in Europe have shown that people with epilepsy have low grades and educational attainment. In our research, the mean number of years of education was $14.07 \pm 2.07$ years. Considering that compulsory education in Japan is 12 years and the average schooling in Japan is 12.8 years, the educational level of the participants in this survey is not low. However, the knowledge means score results showed $40.20 \pm 18.75$ points. This is lower than the average score of $48.50 \pm 19.39$ points in a survey from Germany, where this knowledge scale was developed. This suggests that the sufficient knowledge of epilepsy in Japan has not yet been disseminated.

A psychosocial education program for patients with epilepsy has shown improvements in knowledge. In contrast, the participation rate of patients in self-help groups and educational lectures was at a modest 5.8% in this survey. The low participation rate in these programs may be due not only to the lack of awareness but also to the concentration of facilities and locations in the greater Tokyo area. Since educational programs on specialized diseases are often held predominantly at epilepsy centers, it may be difficult for patients living in rural areas to access them. Japan is an archipelago nation, and the foremost hospitals and university hospitals that provide specialized medical care, not only for epilepsy, are concentrated in urban areas. This study was implemented online. Similarly, online educational programs provided through smartphones and other communication devices could be used to improve knowledge regardless of accessibility and the living environment.

In addition, 61 (19.7%) of the respondents indicated they never disclosed their medical records to others, and they also gave reasons for not participating in self-help groups, unwillingness to reveal their health conditions to the public, resistance to attending such programs due to potential prejudice, possible damage to their self-esteem. Self-stigma prevents people from telling others about their illness, as 49% of respondents have experienced discrimination due to epilepsy. It is anticipated that if knowledge can be provided through online and other methods to reduce self-stigma, participation in self-help groups will be easier.

### 4.3 Limitation

This study is limited because it was conducted among patients registered with an online survey service. Not all patients with epilepsy in Japan participated in our study, focusing on a generation with a high affinity for the Internet. In addition, the survey was based on self-assessment and did not require diagnosed types of epilepsy or an otherworldly assessment of seizure frequency from medical records. Detailed information from existing medical records would be needed to investigate the association between seizure frequency, stigma, and other factors. We should note that the present findings cannot be generalized to all individuals with epilepsy in modern Japanese society.
CONCLUSIONS

Our research identifies previously unknown factors associated with self-stigma among Japanese patients with epilepsy. There was a significant moderate negative correlation between self-esteem and self-stigma and a significant weak negative correlation between seizure frequency and self-stigma. Japanese patients with epilepsy feel a sense of self-stigma even when their seizures are under control. Even though controlling seizures is an important part of treating epilepsy, we must take a long-term view and work to improve the self-esteem of people with epilepsy. In addition, we discovered a significant weak positive correlation between self-esteem and knowledge. To reduce the self-stigma of patients with epilepsy, we consider it essential to provide interventions that assist people with epilepsy in acquiring accurate knowledge about epilepsy and in enhancing their long-term self-esteem. Regarding involvement in self-help groups, educational lectures, and psychosocial education programs, which are said to be beneficial for enhancing epilepsy knowledge, we discovered that self-stigma inhibits participation in Japan. We believe that, in the future, it will be essential to develop educational programs that are more accessible to those with self-stigma.

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CONFLICT OF INTEREST

None of the authors has any conflict of interest to disclose.

DATA AVAILABILITY STATEMENT

The study data are not publicly available.

ETHICAL APPROVAL

The study was conducted after the approval of the study protocol by the institutional review board of Saitama Medical Center, Saitama Medical University (approval no. 2021-106). 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. 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.

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