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## Special Feature Article

### The Reality and towards Effective Intervention for Reducing Self-stigma in Patients with Epilepsy

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## Abstract

Epilepsy is a chronic brain disease caused by various factors. Its main symptom is recurrent seizures (epileptic seizures) caused by excessive discharge of cerebral nerve cells. With a prevalence rate is about 1 in 100, there are about 50 million patients worldwide, and despite being a common neurological disease that is by no means rare, prejudice from society due to its historical background remains deeply rooted. Epilepsy is classified as a psychiatric disorder in the administrative division in Japan, and a psychiatrist should be involved because of its characteristics. Social stigma is internalized to patients and becomes self-stigma. High self-stigma hinders recovery from the disease, as it may cause delays in consultation, difficulty in continuing treatment, and decreased self-esteem and self-efficacy of the patients with epilepsy (PWE). Furthermore, it affects the prognosis and quality of life of PWE.

Since 2016, we have been conducting research to clarify the quality and degree of self-stigma cognition in PWE in Japan, the formation process, and how to deal with

perceived stigma. Patients' self-stigma, depressed mood, and self-esteem are more complexly affected by seizure frequency and treatment status than by mere epilepsy classification. In addition, patients should gain correct knowledge about epilepsy and devise ways to prevent and treat seizures and epilepsy itself. Even if there is an uncontrolled seizure, there is a need for a friend who acknowledges it and is able to listen and consult. It has been shown to have a positive effect on the quality of life by the lives of patients through psychosocial intervention programs.

Herein, we will introduce the research that the authors have conducted so far, and examine the clinical way and future research direction for reducing self-stigma in PWE in Japan.

**Keywords:** epilepsy, prejudice, self-stigma, quality of life, Epilepsy Self-Stigma Scale

## Introduction

In Japan's current “Reiwa” era (beginning in 2019), significant advances have been made in understanding the pathogenesis of symptoms related to epilepsy. The development of new anti-seizure medications has enabled seizure control involving the cessation of seizures in approximately 80% of patients. In addition, the progress in therapies such as vagus nerve stimulation (VNS) and seizure detection systems using wearable devices is helping to establish more comprehensive medical treatment for those with epilepsy. However, even with these advancements, has “prejudice” and “discrimination” against people with epilepsy (PWE) disappeared?

Stigma, defined as prejudice and discriminatory attitudes toward

individuals with certain conditions or attributes, remains prevalent.<sup>7)</sup> Epilepsy-related stigma is common across many cultures and considered one of the primary factors negatively affecting the lives of PWE and their families.<sup>2)8)9)20)22)</sup>

The authors have investigated the current state of self-stigma among PWE in Japan, developing a measurement scale and conducting group psychoeducation programs.<sup>11)13)14)</sup> This article introduces these studies and discusses clinical practices and future research directions aimed at reducing self-stigma among PWE in Japan.

## I. Epilepsy and Stigma

According to the World Health Organization (WHO), epilepsy is defined as “a chronic brain disease

caused by various etiologies and characterized by recurrent seizures (epileptic seizures) due to excessive discharge of cerebral neurons.”<sup>32)</sup> Epilepsy is a common neurological disorder with a prevalence of about 1 in 100 people, with approximately 50 million PWE worldwide, and so it is not uncommon.<sup>24)</sup> It has been documented as far back as 4000 B.C., with serious physical, mental, and social impacts on patients across all ages, races, countries, and geographic regions.<sup>31)</sup>

In response to the history of prejudice due to lack of knowledge, preconceptions, and discrimination against those with epilepsy, WHO, in collaboration with the International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE), launched an international campaign called “Out of the Shadows” in an effort to eliminate the stigma against PWE.

In Japan, “epilepsy” has historically carried a negative image and has been considered one of the “three major mental disorders,” along with schizophrenia and bipolar affective disorder. This perception is partly due to the historical dominance of psychiatrists as primary caregivers for epilepsy. Epilepsy is still classified as a mental disorder in administrative classifications, such as the medical cost assistance system. Even today, despite scientific understanding that epilepsy

originates from neuronal activity in the brain, social prejudice (social stigma) persists in Japan. People with epilepsy continue to face discrimination in areas such as education, employment, and marriage simply because of their condition.<sup>11)</sup>

## II. Effects of self-stigma

Stigma can be broadly divided into social stigma, which is prejudice from society, and self-stigma, which refers to internalized prejudice against one’s own illnesses and attributes. Self-stigma is a complex concept encompassing three elements: cognition, emotion, and behavior.<sup>5)30)</sup>

Regarding mental illness, it is believed that pre-existing social stigma fosters the development of self-stigma once a person is diagnosed, negatively impacting psychosocial functioning.<sup>16)</sup> The importance of understanding stigma in mental illness has led to the development of various assessment scales. Studies have shown that self-stigma, in particular, can delay help-seeking behavior, hinder treatment adherence, and decrease self-esteem and self-efficacy, all of which interfere with recovery from mental illness.<sup>17)</sup>

In Japan, the Devaluation-Discrimination Scale, a prominent measure developed by Link to assess both social and self-stigma, has been translated and used to explore the

impact of self-stigma on mental health conditions.<sup>28)</sup> Self-stigma among PWE, similar to that seen in those with other mental health conditions, significantly influences treatment behaviors, treatment efficacy, the prognosis, and QOL.<sup>1)</sup> Several scales have been developed to measure epilepsy-related stigma, including self-stigma, and various intervention programs have been implemented to reduce stigma.<sup>3)4)6)19)</sup> However, efforts in Japan remain limited.

### III. Investigation of Self-stigma in Patients with Epilepsy

To examine the current state of self-stigma among epilepsy patients, we conducted a study involving outpatients with epilepsy, aged 20 to 65 years.<sup>11)</sup>

Specifically, self-stigma was assessed using the Stigma Scale for Chronic Illnesses (SSCI-8)<sup>21)</sup>. Additionally, semi-structured interviews were conducted to explore patients' perceptions and coping mechanisms related to epilepsy, and measures of depressive symptoms and self-esteem were included. Relevant variables such as epilepsy type (classified according to ILAE standards),<sup>27)</sup> duration of illness, recent seizure frequency, and demographic data (including sex, age, marital status, living arrangements, and employment status) were also collected.

#### 1. Association between seizure frequency and self-stigma

Here, we present the results of quantitative analysis.<sup>13)</sup> Seizure frequency was defined as weekly (less than 7 times a week, 4 or more times a month), monthly (less than 4 times a month, 12 or more times a year), yearly (less than 12 times a year), and seizure suppression (no seizure for 12 months). Effect sizes were calculated to assess the relationships among variables. The associations among depressive symptoms, self-esteem, and seizure frequency were complex, and further complicated by the duration of illness and psychosocial factors. Findings from the authors' study in 2021 indicated a weak negative correlation between seizure frequency and self-stigma.

Traditionally, the relationship between epilepsy and psychiatric symptoms has been considered bidirectional. Poor self-care behaviors are linked to increased seizure frequency, and recurrent seizures are associated with subsequent worsening of depressive symptoms.<sup>9)</sup> Conversely, a sense of control over one's seizures—such as through consistent use of anti-epileptic medications and maintaining a regular lifestyle—has been shown to positively impact self-esteem.<sup>15)</sup> The psychosocial burden of epilepsy exacerbates psychiatric symptoms, which in turn can lead to inadequate self-care and an increase in

the seizure frequency. This cycle can result in a negative perception of having epilepsy, characterized by low self-esteem, which may further reinforce self-stigma.

## 2. Self-stigma in patients with epilepsy (results of qualitative analysis)

Next, we present the elements of self-stigma experienced by epilepsy patients, as revealed through semi-structured interviews. From 206 verbatim responses, 74 codes (“< >”) were identified and classified into 22 subcategories (“[ ]”) and three main categories: self-stigma, perception of social stigma, and actual distress/concern (Table 1). Below is a detailed description of the self-stigma categories identified in the qualitative analysis.

Self-stigma among PWE encompasses not only negative beliefs [(ii) negative perceptions about the disease/diagnosis of epilepsy], such as “I am not capable” and “I am weak”, but also (iii) Negative cognitions about epileptic seizures, such as <an epileptic seizure causes “froths and falls”>, <a seizure would be a nuisance to others>, and <people witnessing a seizure would feel uncomfortable>, etc.

These negative emotions contribute to feelings of: (v) [difficulty in telling people that I have epilepsy], such as <difficulty disclosing epilepsy>,

<hesitance to tell teachers or colleagues about the diagnosis>, <difficulty disclosing the condition to family members>, <hesitance to tell teachers or colleagues about the diagnosis>, and <reluctance to inform other healthcare providers of the condition>. These feelings often lead to a behavioral shift where patients feel compelled to (vi) conceal their epilepsy, with feelings such as <I want to hide my epilepsy diagnosis>, <I avoid taking medication in public>, or <I want to conceal my hospital visits for epilepsy treatment>.

Such negative behavioral adaptations are linked to affective components [(vii) lack of confidence in social interactions] and [(viii) diminished general self-confidence]. Additionally, beyond behavioral concealment, a cognitive component [(ix) negative evaluation of one’s life to date] was also observed, where patients expressed sentiments of <giving up many aspects of life because of epilepsy>.

These elements of cognition, emotion, and behavior related to self-stigma in epilepsy are summarized (Figure).

## 3. Coping strategies for epilepsy

Coping strategies for epilepsy are also discussed here. Patients are encouraged not only to adopt measures to avoid seizures in their daily lives, but also to seek information about epilepsy. In addition, coping strategies include

attitudes, like: <I want to address my epilepsy because it is my problem> and <I try to think of epilepsy as a path I have chosen>, reflecting an acceptance of epilepsy as part of their life. Some patients also coped by “trying not to think about epilepsy” as a way to avoid emotional distress.

The most commonly expressed need was for companionship. Coping strategies included not only a <need for friends> who also have epilepsy but also a <need for a space to talk> openly about their condition. Many patients expressed a belief that by acquiring accurate knowledge about epilepsy and working to prevent seizures, while also accepting the reality of occasional seizures, they could reduce the stigma associated with their illness.

It became evident that patients needed a peer group with whom they could discuss and accept their seizures and someone supportive who would simply listen. This companionship and acceptance were seen as crucial in managing stigma and enhancing their QOL.

#### **IV. Epilepsy Self-stigma Scale**

The Epilepsy Self-stigma Scale (ESSS)<sup>14)</sup> was developed to measure self-stigma focusing on “epilepsy” and provide a convenient assessment scale that can be used in outpatient settings.

The questionnaire was developed based on the results of the aforementioned qualitative analysis,<sup>11)</sup> and exploratory factor analysis was conducted based on data obtained from 100 PWE attending outpatient clinics across multiple medical institutions.

The questionnaire comprises three factors and eight items (Table 2). Items 1-4 correspond to “internalization of stigma,” items 5 and 6 address “social incomprehension,” and items 7 and 8 relate to “secrecy.” A higher total score indicates stronger self-stigma regarding epilepsy. By calculating scores for each factor, it becomes possible to assess which aspects of self-stigma are more pronounced from various perspectives. ESSS has demonstrated high retest reliability and construct validity, particularly in relation to depressive symptoms and self-esteem. Importantly, we identified no significant correlation between the objective assessments of self-stigma by the patients’ attending physicians and total scores on ESSS. This finding is particularly meaningful, as self-stigma is inherently an internalized phenomenon, highlighting the challenges of accurately assessing patients’ self-stigma solely within the consultation setting.

We anticipate that this scale will be actively utilized in daily clinical practice and intervention research to better

understand and address self-stigma in patients with epilepsy.

### **V. Efforts to Reduce Self-stigma in Patients with Epilepsy**

Finally, we present an initiative involving a group psychoeducation program aimed at reducing self-stigma among PWE.<sup>12)</sup> We developed a group psychoeducation program called Epi-School, which is based on the MOSES (Modulares Schulungsprogramm Epilepsie) model originally established in Germany in 1998, and adapted to fit the culture and medical context of Japan.<sup>18)23)26)29)</sup> This program focuses on interventions designed to enhance patients' understanding of their condition, facilitate the formation of peer support groups, and increase their sense of control over their illness, thereby fostering self-efficacy, in light of findings from our previous self-stigma survey.<sup>11)</sup>

The program was conducted with 11 PWE aged 18 years or older and 12 family members, all attending the outpatient psychiatry department of a university hospital. Participation was limited to either the patient or, with the patient's consent, family members. The program consisted of group sessions lasting 2 to 3 hours each, with a total of three sessions over a period of two months. Topics covered included the epidemiology and basic understanding

of epilepsy, diagnosis and treatment options, self-management strategies, and psychosocial considerations. The sessions were facilitated by two dedicated trainers (a specialist in epilepsy and psychiatric nurse), with support from a multidisciplinary team that included pharmacists, licensed psychologists, and mental health workers, tailored to the contents of each session.

Results from the intervention indicated a significant increase in knowledge about epilepsy among both patients and their relatives before and after the program. Positive changes were also noted in overall life satisfaction and psychological acceptance of epilepsy as a chronic condition. In free-response questionnaires, many participants reported improvements in their understanding of the disease and coping strategies, as well as shifts in their psychological outlook. These findings align with results from similar intervention programs conducted in other countries.<sup>18)</sup>

The results suggest that group psychoeducation programs in Japan not only enhance knowledge about epilepsy but also promote positive attitudes toward the condition and improve QOL of patients and their families. Further research with a control group is required to accumulate evidence on the

effectiveness of group psychoeducation programs, including Epi-School, in a Japanese context.

### Conclusion

In this article, we have described the current situation regarding the stigma associated with epilepsy and efforts being made to reduce it in Japan, drawing on the authors' research findings. We believe that it is imperative for healthcare professionals involved in the treatment of people with epilepsy to actively combat the persistence of misinformation, superstition, and prejudice surrounding the condition.

As highlighted, there remains a paucity of studies focused on self-stigma in epilepsy patients within Japan. Therefore, there is a critical need to develop evaluation and intervention methods informed by findings from international research, tailored to the cultural context and specific realities of epilepsy treatment in Japan.

We hope that this report will contribute to the expansion of research initiatives aimed at reducing self-stigma among PWE, ultimately improving their QOL and overall treatment outcomes.

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表1 てんかん患者のセルフステイグマ (質的分析結果)

大カテゴリ	小カテゴリ (内容)
I. セルフステイグマ	(i) てんかんに関する内容不明確でネガティブな認知・感情 (ii) てんかんという疾患・診断に関するネガティブな認知・感情 (iii) てんかん発作に関するネガティブな認知・感情 (iv) 精神科受診に対する嫌悪感 (v) てんかんであることを言にくい (vi) てんかんであることを隠したい (vii) 社会生活の自信がない (viii) 全般的な自信の低下 (ix) これまでの人生のネガティブな評価
II. 社会的ステイグマの認知	てんかんという疾患と、発作に対する社会的偏見
III. 現実の苦痛・悩み	てんかんによる苦痛、発作への心配・恐怖・悩み

Table 1 Self-stigma of epilepsy patients (results of qualitative analysis)

Major category, Minor category (content)

I. Self-stigma

- (i) Unclear and negative cognitions and feelings about epilepsy
- (ii) Negative cognitions/feelings about the disease/diagnosis of epilepsy
- (iii) Negative perceptions and feelings about epilepsy seizures
- (iv) Aversion to seeing a psychiatrist
- (v) Difficulty in telling others that they have epilepsy
- (vi) Wanting to hide the fact that they have epilepsy
- (vii) Lack of confidence in social life

(viii) General lack of self-confidence

(ix) Negative evaluation of life to this point

## II. Recognition of social stigma

Social prejudice against epilepsy and seizures

## III. Real-life distress and worries

Distress from epilepsy, worries and fears about seizures

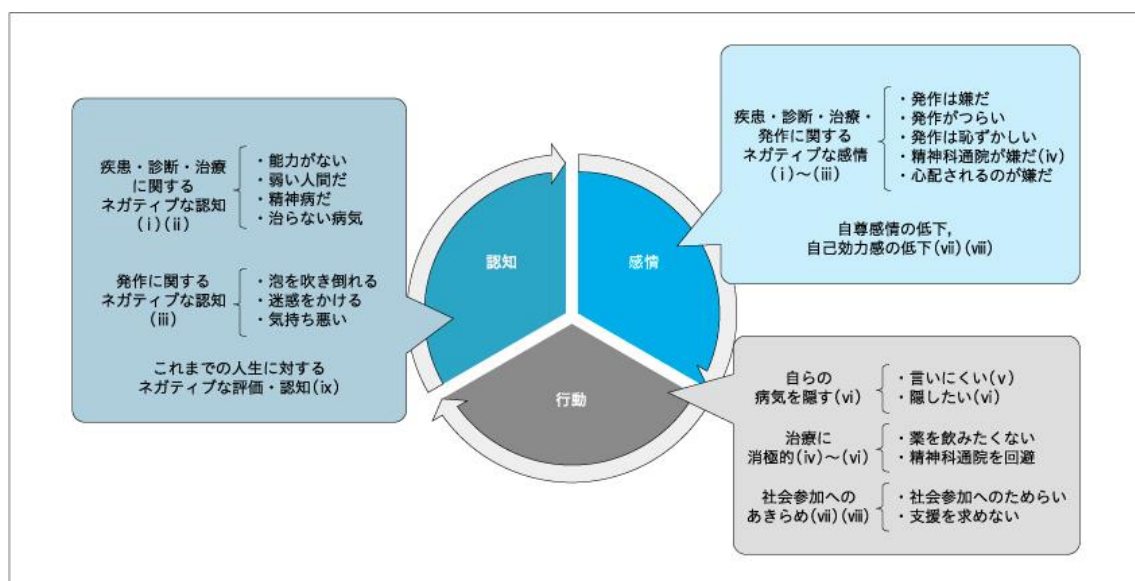


図 てんかんのセルフスティグマの認知, 感情, 行動のまとめ (質的分析結果)  
ローマ数字は表1と一致.

Fig. Summary of cognition, emotion, and behavior due to self-stigma of epilepsy patients (results of qualitative analysis).

Roman numerals correspond to Table 1.

表2 日本語版てんかんセルフスティグマスケール (8 items)

この質問票は、あなたの「てんかん」という病気に対して、あなた自身がどう思っているか、意見をお伺いします。下の4段階の数字を使って以下の文章にどの程度そう思うか、あるいはそう思わないかを、文章の右にある数字のうち最も当てはまると思うものを1つ選んでください。

	全くそう 思わない	少し そう思う	そう思う	非常に そう思う
1. てんかん発作に関連する交通事故などのニュースを聞くと、自分のことをいわれているように感じる	1	2	3	4
2. てんかんのために、周囲から差別される	1	2	3	4
3. てんかんがあると、恥ずかしい思いをすることがある	1	2	3	4
4. てんかんがあることで、自分は普通の人とは違うと感じる	1	2	3	4
5. てんかんの苦痛や発作への心配は他の人にはなかなか理解してもらえない	1	2	3	4
6. てんかんという病気について、正しい情報を持っている人が少ない	1	2	3	4
7. てんかんであることを、他の人には言いたくない	1	2	3	4
8. てんかんで通院・治療していることは隠しておきたい	1	2	3	4

(文献13より引用)

Table 2 Japanese version of Epilepsy Self-stigma Scale (8 items)

This questionnaire asks your opinion about your “epilepsy.” Please choose the number to the right of the statement that best describes how much you agree or disagree with the following statements using the four-numbered scale below.

Not at all (1), Slightly agree (2), Agree (3), Very much so (4)

1. When I hear news about traffic accidents related to epilepsy seizures, I feel as if it is referring to me
2. I am discriminated against by others because of my epilepsy
3. I sometimes feel embarrassed when I have epilepsy
4. I feel that I am different from others because of epilepsy
5. It is difficult for others to understand the pain of epilepsy and worry about seizures
6. Few people have accurate information about epilepsy
7. It is difficult to tell others that I have epilepsy
8. I want to hide the fact that I have epilepsy

(Adapted from Reference 13)