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Research article

Internet survey on knowledge and perceptions of epilepsy among the general public in Japan

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ABSTRACT

Objective: To improve the life quality of people with epilepsy, it is necessary to provide comprehensive epilepsy care and disseminate accurate information related to epilepsy to the public. In Japan, reports of traffic accidents involving people with epilepsy started to draw attention in the media in 2011. Ever since that, the association between the image of epilepsy from the general public, "Epilepsy," and "Danger," was more robust in 2013. Since 2017, no previous surveys have examined the perceptions and knowledge of epilepsy among the public in Japan. As an essential source of information for epilepsy care, we conducted a nationwide Internet-based survey to elucidate the current state of knowledge and perceptions of epilepsy among the public without epilepsy in Japan.
Methods: We conducted an online survey from July 29 to August 2, 2021, with 213 respondents (115 male, 97 female, and one unidentified; mean age: 50.52 ± 12.34 years) registered with an online survey service in Japan. In this survey, we first questioned whether or not a respondent had epilepsy, and then those with epilepsy were excluded from participation. We collected basic demographic information, administered the Epilepsy Knowledge Scale (18 items), and asked the open-ended response question, *"What kind of disease do you think epilepsy is? If you do not know, please describe epilepsy in your words."* We adopted quantitative text analysis using KH Coder3 and co-occurrence network analysis to examine the connections between words.
Results: Among the respondents, 92% have heard of epilepsy, and 26.8% have observed an epileptic seizure before the survey. The knowledge scale yields an average score of 27.96 ± 21.3 (out of 100), with the question with the highest percentage of correct responses being "People with epilepsy are just as capable as other people" at 51.64%. The question with the lowest percentage of correct responses was "If the person with epilepsy only has seizures during sleep, the person can have a driver's license," at 9.85%. The average number of Japanese characters responding to open-ended text questions was 10.45 ± 8.87 characters (including Kanji, Hiragana, and Katakana). We found that the word "froth" appeared more frequently with experience of observing a seizure, and the words "occur" and "brain" appeared more frequently with higher knowledge of epilepsy. Furthermore, comparing the sources of information from what they learned about epilepsy, the words "seizure," "faint," and "consciousness" appeared more frequently in school, with family and friends, and in newspapers and television, respectively.
Conclusion: We identified the level of knowledge and perceptions of epilepsy among the general public in Japan in 2021. By analyzing the qualitative aspects of open-ended text responses, we gathered information that might be useful for informing the public of future efforts to provide accurate information related to epilepsy.

1. Introduction

The stigma associated with epilepsy is pervasive in numerous cultures [1] as one of the most significant difficulties affecting the lives of people with epilepsy (PWE) and their families [2, 3, 4, 5]. According to a report by the International League Against Epilepsy (ILAE) Task Force on Stigma in Epilepsy in 2022 [6], stigma varies substantially by location, and a lack

of epilepsy knowledge and educational opportunities contribute to the development of stigma.

Epilepsy is a common diagnosis in Japan, while stigma and prejudice remain widespread in Japanese society [7, 8]. The term for epilepsy in Japanese, "ten-kan (癲癇)," indicates the negative meaning of "mad" and "a violent temperament that is apt to be infatuated." In addition, epilepsy is classified as a psychiatric disorder by the relevant authority (Ministry of health, labor, and Welfare) in Japan. When PWE acquires welfare assistance, it is necessary to obtain the mental disability certificate as a mental illness. Even though psychiatrists are required to participate in treating epilepsy-related psychiatric symptoms, some PWE may refuse to visit a psychiatrist owing to the potential prejudice. Due to stigmatization and societal conceptions of epilepsy, PWE might be discouraged from receiving treatment and participating in social activities.

Furthermore, in Japan, reports of traffic accidents related to epileptic seizures began to draw attention in the media in 2011 [10, 11,12]. On April 18th, 2011, severe car accidents in Tochigi Prefecture, Japan caused by PWE resulted in fatalities, including six children. In 2012, another collision caused by a PWE caused the casualties of eight pedestrians. These tragedies left an indelible mark on the Japanese social phenomenon. Following these tragic occasions, scholars investigated the recognition and perceptions of epilepsy for the general public [10, 11, 14, 15]. It is more robust to perceive the association between the image of epilepsy from the general public, "Epilepsy," and "Danger," in 2013. Moreover, the public image towards epilepsy and prejudice has deteriorated due to these incidents above in Japanese society.

As a result, two legal regulations on PWE drivers were updated in 2014 [13]. This version includes additional requirements, such as the need for drivers to disclose medical issues (including epilepsy) on their licenses, with penalties for dishonest assertions. Additionally, a novel voluntary notification system allows physicians to report illegal drivers with false confessions. The Japan Epilepsy Association recommended that professionals, patients, and their families review and comply with the text of these statutes.

After toughening the law in Japan, the number of rejected driving license applications for PWE increased remarkably. However, the number of collisions caused by drivers with epilepsy did not turn to decrease [16].

To reduce stigma and enhance the life quality of PWE, we must provide comprehensive treatment for epilepsy and disseminate accurate information about epilepsy among the general population. Epilepsy Month started in 1983 as a "month to strengthen awareness-raising activities connected to epilepsy," aiming to increase national knowledge of epilepsy. Across Japan, various epilepsy-related educational activities are held during Epilepsy Month, including national epilepsy conventions, lectures, and street petition drives. The Japanese government constantly deliberates on eliminating discrimination against people with disabilities and disorders, including epilepsy [9]. In addition, Japan enacted a novel law outlawing discrimination against people with disabilities, including epilepsy, starting in April 2016.

With the spread of the Internet in the last decade, the general public can freely obtain information from various media on the Internet. In this research, we hypothesized that all generations had acquired the appropriate knowledge of epilepsy as more information is currently available. The gradual decline in media coverage of traffic accidents associated with PWE was observed from 2011 to 2016. Since 2017, no nationwide reports have been on Japan's general public's knowledge and perceptions of epilepsy. In our study, we conducted a nationwide Internet-based survey of Japanese people without epilepsy to evaluate their level of knowledge about epilepsy and their genuine opinions about it. Notably, we can use this information to identify the insufficient understanding of epilepsy among the general public in Japan, as well as misguided perceptions and insufficient knowledge, and work to contribute more to this discipline.

2. Methods

2.1. Participants and procedure

We surveyed the general public registered with an online research survey service (Intage Inc. Tokyo, Japan) using an online questionnaire. This study collected responses from people with no epilepsy across seven regions of Japan. We excluded people with epilepsy from completing the questionnaire as an exclusion criterion by requiring the first question, "Do you have epilepsy?". 213 people completed the questionnaire (115 male, 97 female, and one unidentified; mean age 50.52 ± 12.34) in contrast to the total registered users on the questionnaire site as 28,315 (total number of registrants to the survey service, including people with epilepsy) from July 29, 2021, to August 2, 2021. We did not financially sponsor respondents with special compensation for answering this survey.

2.2. Measures

We requested participants to complete the questionnaire to provide information about age, gender, educational history, employment status, living style, the Epilepsy Knowledge Scale (EKS) [17, 18], and one open-ended question: *"What kind of disease do you think epilepsy is? If you do not know, please describe epilepsy in your words."* In addition, we also inquired respondents about their experience of hearing about epilepsy, where they learned or heard about epilepsy (at school, from family/friends, in the newspaper/TV, on the Internet), and the experience of seeing an epileptic seizure.

The EKS 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 showed 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 in this research was voluntary, and information was collected anonymously after obtaining consent from each respondent by assuring confidentiality throughout data collection.

2.4. Data analysis

We analyzed data from 206 of 213 respondents after excluding seven respondents who answered "none" in the open-ended response section. We used the free text analysis software K.H. Coder 3 (available for download at https://khcoder.net/) [19, 20] to conduct the qualitative analysis of the open-ended response data. Before the analysis, we applied coding rules to the text data processor to categorize similar words into the same word group (Table 1). We defined word groups that appeared more than three times in the open-ended responses as frequent words. In addition, we used a co-occurrence network analysis performed to visualize the connections between words. We used the Jaccard coefficient as a measure of connection. Coefficients closer to 1 indicated a more robust association, whereas coefficients closer to 0 indicated a weaker association [21, 22, 23]. We defined a Jaccard coefficient of 0.2 or higher as the criterion for a meaningful association between the words and groups. We also carried out a chi-squared test for the ten most frequent words in each group and compared the frequency of the words among the groups using a chi-square test.

In addition, we split the results of the EKS score into two groups, one with a high score (≥22.24) and one with a low score (<22.24) based on the median total EKS score of 22.24, and compared with a t-test for gender, employment status, residential status, observed an epileptic seizure, and information source (school, family/friends, newspaper/TV, internet), respectively, high and low knowledge. As for age, we

Table 1. Coding rules.

Coded Words	Described words
Suddenly	Suddenly, rapidly, unexpectedly, quickly, immediately
Consciousness	Consciousness, awareness, sanity
Occur	Happen, occur
Lose	Lose, loss, pass out
Convulsion	Convulsion, twitch, cramp, tremble
Illness	Illness, disease, sickness
Brain	Brain, head, mind,
Faint	Fall, faint, succumb
Body	Body, whole body
Develop	Develop, present

categorized the respondents into four groups (I: under 39, II: 40–49, III: 50–59, and IV: above 60) and performed the one-factor analysis of variance for high and low knowledge.

We adopted R v4.1.1 software for quantitative statistical analyses [24].

3. Results

3.1. Participants' characteristics

The questionnaires were answered by 213 public (115 male, 97 female, and one unidentified; mean age 50.52 ± 12.34). Other attributes and scale scores are shown in Table 2.

3.2. Knowledge of epilepsy among the general public

Among the respondents, 196 out of 213 (92%) have heard of epilepsy. Of 196 respondents, 35 (17.9%) have learned about epilepsy at school; 79 (40.3%) from family or friends; 89 (45.4%) from TV or newspapers; and 28 (14.3%) have learned about epilepsy from the Internet. Sixteen respondents (8.2%) answered "other" because they have acquaintances with epilepsy at work or in their families. Seven respondents stated that they had a family member with epilepsy.

Of the 213 respondents, 57 (26.76%) have observed an epileptic seizure.

Respondents' average EKS score was 27.96 ± 21.3 (out of 100), and 41 (19.2%) respondents could select the correct answer for more than

Table 2. Participants' characteristics and EKS scores (N = 213).

Variables	Mean (S.D.)
Age, years	50.52 (12.34)
Range	19–78
Gender	
Female	45.5 (%)
Male	54.0 (%)
Unidentified	0.5 (%)
Duration of education	14.15 (2.00)
Occupational status	
Employed	64.3 (%)
Laid off	6.1 (%)
Unemployed	25.4 (%)
Homemaker	2.3 (%)
Student	1.9 (%)
Living status	
Alone	22.5 (%)
With family or others	77.5 (%)
EKS	27.96 (21.3)

Abbreviations: EKS, Epilepsy Knowledge Scale; S.D., standard deviation.

half of the items on the knowledge scale. The EKS question with the highest percentage of correct answers was "People with epilepsy are exactly as capable as other people," with a rate of 51.64%. The question with the lowest percentage of correct answers was "If the occurrence of epilepsy is limited to the period of sleep, the person can keep a driver's license," with a rate of 9.85%. The EKS questions are presented in Table 3 in order of response rate.

The results of the t-test between the epilepsy knowledge scale (high score ($\geq$22.24) and one with low score (<22.24)) and the respondents' background showed no significant difference in gender (male and female) (t = -0.57, P = 0.57), significant difference in employment status (employed or unemployed) (t = -2.94, P = 0.00), no significant difference for type of residence (t = -0.23, P = 0.82), no significant difference for having seen seizures (t = -1.65, P = 0.10), no significant difference for source of information (school) (t = -0.98, P = 0.33), no significant difference for source of information (family/friends) (t = -0.25, P = 0.00). 25, P = 0.80), no significant difference in information source (newspaper/TV) (t = 0.12, P = 0.90), and no significant difference in information source (Internet) (t = -1.87, P = 0.07). For age ((I: under 39, II: 40–49, III: 50–59, and IV: above 60)), the analysis of variance for one factor showed no significant difference (F = 0.76, P = 0.52).

3.3. Qualitative analysis of perceptions of epilepsy

The results of the open-ended text responses indicated that the shortest response was two Japanese characters in length ("seizure," "fear," and "convulsion"), and the longest, including punctuation, was 53 characters. Specifically, the most extended response was, "Because of the sudden onset of seizures, the support of those around the person is necessary. Therefore, it is important to know what symptoms to be expected and how to deal with them." Among the respondents, 15 answered "not sure" or "do not know." The mean number of characters was 10.45, ranging from 2 to 53, with a standard deviation of 8.87.

3.3.1. Word frequency and connections

Based on the coding rules, we extracted 213 different words from the open-ended response data. Table 4 lists the words that appeared more than three times. The five most frequently appearing words, listed in order from the most frequent, were "seizure," "suddenly," "consciousness," "occur," and "lose."

In the co-occurrence network, the four most frequent words ("seizure," "consciousness," "occur," and "lose") all had a strong association with the word "suddenly" (Jaccard coefficients 0.22–0.28). In addition, "illness" had a strong association with "brain" (Jaccard coefficient 0.41) (Figure 1).

3.3.2. Comparison of demographic variables

We compared the frequency of occurrence of frequent words with demographic variables (age, gender, employment status, and living style). Respondents were grouped into the following age groups: I: under 39 (n = 40), II: 40–49 (n = 59), III: 50–59 (n = 62), and IV: above 60 (n = 52). Employment status was grouped into employed (including those on leave) (n = 150) and unemployed (including students and homemakers) (n = 63). The results showed that the word "illness" solely in living style was mentioned significantly more frequently in the single-resident group compared with the cohabitant group (X^2 = 3.88, df = 1, P = 0.049) (Table 5). Other demographic variables did not show significant frequency differences among all words (Appendix 1-3).

3.3.3. Comparison of perceptions by presence, degree, and source of knowledge of epilepsy

We examined whether there was a difference in perceptions of epilepsy depending on the following attributes by comparing the frequency of occurrence of different words:

1. the presence or absence of knowledge about epilepsy;

Table 3. Percentage of correct answers for items of the epilepsy knowledge scale for the general public (N = 213).

	Question	Answer key	The sum of people with correct answers	Accuracy
1	People with epilepsy are exactly as capable as other people.	○	110	51.64%
2	In most situations, physicians can control seizures with medications.	○	106	49.77%
3	Epilepsy is a mental illness.	×	96	45.07%
4	People with potential seizures should not swim without an escort.	○	80	37.56%
5	All people with epilepsy have similar symptoms.	×	69	32.39%
6	The seizure could occur on anybody under certain circumstances.	○	69	32.39%
7	People with epilepsy can actively participate in sports.	○	66	30.99%
8	All seizures can destroy many neurons in the brain.	×	63	29.58%
9	Epileptic seizures always make the person lose consciousness.	×	58	27.23%
10	All people with seizures should avoid machine operations.	×	56	26.29%
11	All people with epilepsy should avoid flashlight and strobe stimuli (discos, TV, etc.).	×	52	24.41%
12	Epilepsy can always be diagnosed via EEG.	×	50	23.47%
13	Once seizures have not occurred for several months, the patients can reduce the dose of antiepileptic drugs of their own will.	×	42	19.72%
14	When applying for a job, people with epilepsy always have to confess their epilepsy.	×	40	18.78%
15	People with epilepsy should avoid strenuous work since it can induce seizures.	×	35	16.43%
16	A higher dose of medication will be expected if a seizure is anticipated.	×	29	13.62%
17	Blood samples can be used to measure blood levels of antiepileptic drugs in the body.	○	29	13.62%
18	If the occurrence of epilepsy is limited to the period of sleep, the person can keep a driver's license.	○	21	9.85%

2. the degree of knowledge;
3. the source of information about epilepsy.

The frequency of occurrence of the word "froth" was significantly higher for those who had observed a seizure than the others ($X^2 = 4.88$, df = 1, P = 0.03) (Table 6).

The EKS scores were dichotomized at the median (22.24) and compared between the high-scoring group (n = 127) and the low-scoring group (n = 86). The high-scoring group had significantly more frequent occurrences of the words "occur" ($X^2 = 4.09$, df = 1, P = 0.04) and "brain" ($X^2 = 6.55$, df = 1, P = 0.01) compared with the low-scoring group (Table 7).

In a comparison of the source of information about epilepsy, the word "seizure" was mentioned significantly more frequently in the group that reported learning about epilepsy at school ($X^2 = 5.10$, df = 1, P = 0.02)

Table 4. List of words used over three times.

Extracted word	Counts	Extracted word	Counts	Extracted word	Counts
Seizure	73	Froth	18	Drive	3
Suddenly	60	Body	6	Breathing	3
Consciousness	55	Abnormal	6	Cure	3
Occur	54	Develop	6	Disturbance	3
Lose	46	Medicine	6	Nerve	3
Convulsions	40	Mouth	5	Body move	3
Illness	32	Symptoms	5	Onset	3
Brain	26	Mental illness	4	Fear	3
Faint	21	Take (medicines)	3	Control	3

(Table 8). The group that answered that the respondents learned about epilepsy from a family member or friend used the word "consciousness" significantly less frequently ($X^2 = 4.04$, df = 1, P = 0.04). In contrast, the term "faint" was used significantly more frequently ($X^2 = 8.08$, df = 1, P = 0.00) (Table 9). In the group that answered that they learned about epilepsy from newspapers and TV, the words "consciousness" ($X^2 = 4.30$, df = 1, P = 0.04) and "lose" ($X^2 = 6.75$, df = 1, P = 0.01) appeared significantly more frequently (Table 10). In contrast, there were no significant results when the Internet was reported as an information source (Appendix 4).

4. Discussions

Our survey reveals the knowledge and perceptions of epilepsy among the general public without epilepsy in Japan in 2021. Among the respondents, 92% have heard of the term "epilepsy," and 26.8% had observed an epileptic seizure, yet the epilepsy knowledge scale yielded an average score of 27.96 ± 21.3 (out of 100). In Japan, the knowledge scores of epilepsy for the general public were lower than the average score of 48.50 ± 19.39 points reported in a previous one (developed by EKS) in Germany [10]. Our results indicate that the general public in Japan is aware of epilepsy but lacks sufficient knowledge of the disease.

In the following, we consider the results of a more detailed qualitative analysis.

4.1. Knowledge of epilepsy among the general public in Japan

Previous studies in Japan reported that from 2013 to 2017, knowledge about epilepsy was higher among those who had read or heard
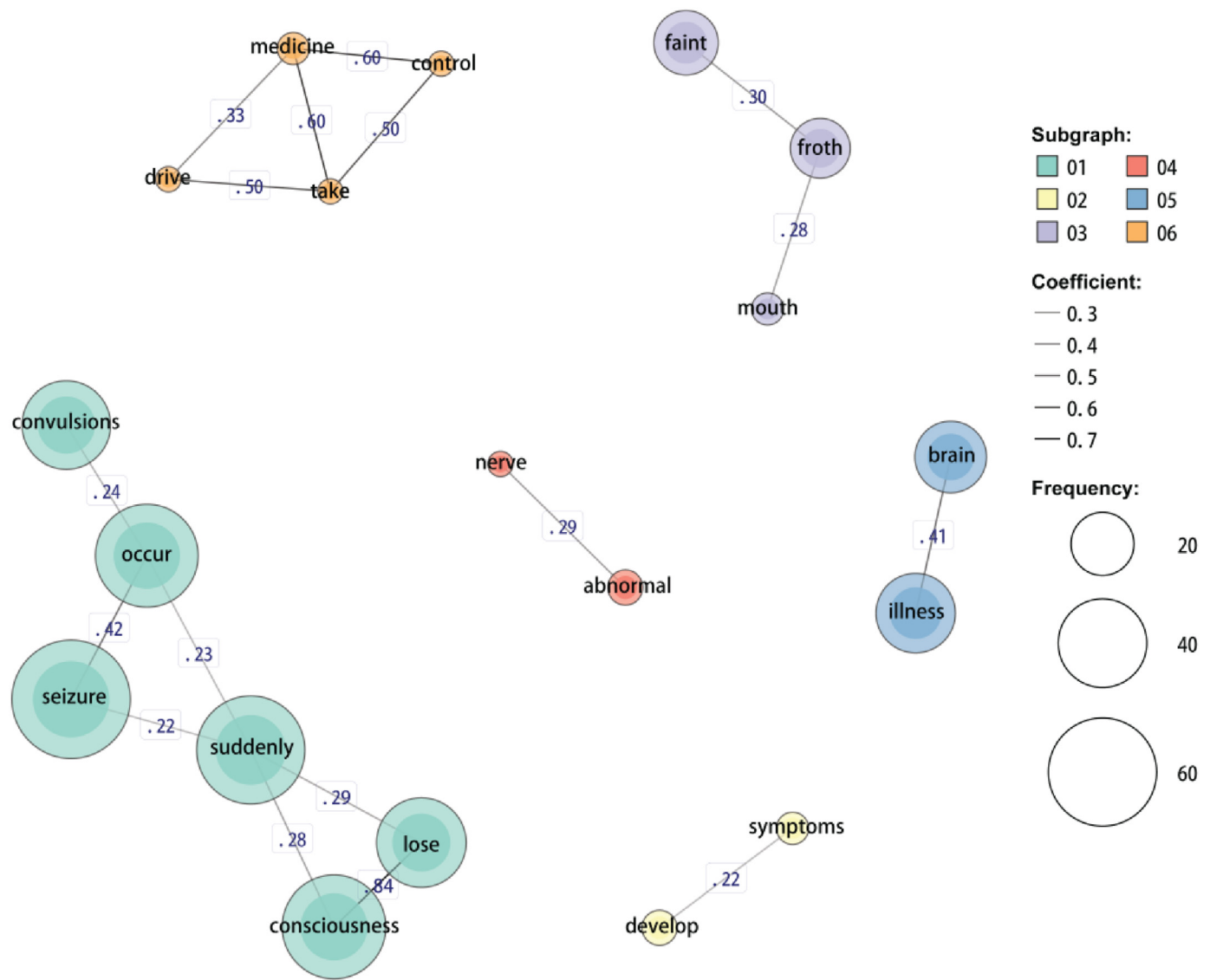
Figure 1. Co-occurrence network diagram.

Table 5. Comparison by living status (N = 213).

Frequent words (top 10)	Frequency (%)		X^2	P
	With family or partners (N = 150)	Alone (N = 63)		
Seizure	56 (33.94%)	16 (33.33%)	0.00	>0.99
Suddenly	50 (30.30%)	10 (20.83%)	1.21	0.27
Consciousness	47 (28.48%)	8 (16.67%)	2.13	0.14
Occur	41 (24.85%)	13 (27.08%)	0.02	0.90
Lose	40 (24.24%)	6 (12.50%)	2.37	0.12
Convulsions	32 (19.39%)	8 (16.67%)	0.05	0.83
Illness	20 (12.12%)	12 (25.00%)	3.88	0.049
Brain	21 (12.73%)	5 (10.42%)	0.03	0.86
Faint	18 (10.91%)	3 (6.25%)	0.46	0.50
Froth	16 (9.70%)	2 (4.17%)	0.84	0.36

Table 6. Comparison by whether or not have experience observing a seizure (N = 196).

Frequent words (top 10)	Frequency (%)		X^2	P
	Have seen seizures (N = 57)	Never have seen seizures (N = 139)		
Seizure	20 (35.09%)	51 (36.69%)	0.00	0.96
Suddenly	19 (33.33%)	39 (28.06%)	0.32	0.57
Consciousness	15 (26.32%)	36 (25.90%)	0.00	>0.99
Occur	21 (36.84%)	33 (23.74%)	2.85	0.09
Lose	11 (19.30%)	31 (22.30%)	0.08	0.78
Convulsions	10 (17.54%)	30 (21.58%)	0.20	0.66
Illness	9 (15.79%)	21 (15.11%)	0.00	>0.99
Brain	8 (14.04%)	17 (12.23%)	0.01	0.91
Faint	10 (17.54%)	11 (7.91%)	2.98	0.08
Froth	9 (15.79%)	7 (5.04%)	4.88	0.03

about epilepsy, witnessed an epileptic seizure, had an acquaintance with epilepsy, or had a PWE in the family [14]. However, in our study, this significant difference was not observed. We identified significant differences in sufficient knowledge of epilepsy in employment status (employed, unemployed) (t = −2.94, P = 0.00). Regarding how much

people knew about epilepsy by employment status, the results suggested that people who worked had more contact with others and more opportunities to learn or hear about epilepsy. There was no significant difference other than employment status because the spread of the

Table 7. Comparison in EKS scores (N = 213).

Frequent words (top 10)	Frequency (%)		X^2	P
	High EKS score (N = 127)	Low EKS score (N = 86)		
Seizure	45 (35.43%)	27 (31.40%)	0.22	0.64
Suddenly	38 (29.92%)	22 (25.58%)	0.29	0.59
Consciousness	39 (30.71%)	16 (18.60%)	3.32	0.07
Occur	39 (30.71%)	15 (17.44%)	4.09	0.04
Lose	32 (25.20%)	14 (16.28%)	1.91	0.17
Convulsions	29 (22.83%)	11 (12.79%)	2.77	0.10
Illness	24 (18.90%)	8 (9.30%)	2.99	0.08
Brain	22 (17.32%)	4 (4.65%)	6.55	0.01
Faint	12 (9.45%)	9 (10.47%)	0.00	0.99
Froth	9 (7.09%)	9 (10.47%)	0.38	0.54

Note. The patients belong to either high (≥22.24) or low score groups (<22.24) based on the median total EKS score.

Table 8. Comparison by the source of information about epilepsy (at school) (N = 196).

Frequent words (top 10)	Frequency (%)		X^2	P
	At school (N = 35)	Not at school (N = 161)		
Seizure	19 (54.29%)	52 (32.30%)	5.10	0.02
Suddenly	9 (25.71%)	49 (30.43%)	0.12	0.73
Consciousness	5 (14.29%)	46 (28.57%)	2.35	0.13
Occur	12 (34.29%)	42 (26.09%)	0.60	0.44
Lose	3 (8.57%)	39 (24.22%)	3.31	0.07
Convulsions	5 (14.29%)	35 (21.74%)	0.58	0.45
Illness	7 (20.00%)	23 (14.29%)	0.35	0.55
Brain	7 (20.00%)	18 (11.18%)	1.30	0.26
Faint	2 (5.71%)	19 (11.80%)	0.57	0.45
Froth	1 (2.86%)	15 (9.32%)	0.86	0.36

Table 9. Comparison by the source of information about epilepsy (from family/friends) (N = 196).

Frequent words (top 10)	Frequency (%)		X^2	P
	From family/friends (N = 79)	Not from family/friends (N = 117)		
Seizure	30 (37.97%)	41 (35.04%)	0.07	0.79
Suddenly	23 (29.11%)	35 (29.91%)	0.00	>0.99
Consciousness	14 (17.72%)	37 (31.62%)	4.04	0.04
Occur	24 (30.38%)	30 (25.64%)	0.32	0.57
Lose	12 (15.19%)	30 (25.64%)	2.47	0.12
Convulsions	15 (18.99%)	25 (21.37%)	0.05	0.82
Illness	11 (13.92%)	19 (16.24%)	0.06	0.81
Brain	11 (13.92%)	14 (11.97%)	0.03	0.85
Faint	15 (18.99%)	6 (5.13%)	8.08	0.00
Froth	9 (11.39%)	7 (5.98%)	1.19	0.28

Table 10. Comparison by the source of information about epilepsy (newspaper/TV) (N = 196).

Frequent words (top 10)	Frequency (%)		X^2	P
	Newspaper/TV (N = 89)	Except for newspaper/TV (N = 107)		
Seizure	35 (39.33%)	36 (33.64%)	0.46	0.50
Suddenly	33 (37.08%)	25 (23.36%)	3.75	0.05
Consciousness	30 (33.71%)	21 (19.63%)	4.30	0.04
Occur	21 (23.60%)	33 (30.84%)	0.94	0.33
Lose	27 (30.34%)	15 (14.02%)	6.75	0.01
Convulsions	21 (23.60%)	19 (17.76%)	0.69	0.41
Illness	12 (13.48%)	18 (16.82%)	0.20	0.65
Brain	11 (12.36%)	14 (13.08%)	0.00	>0.99
Faint	7 (7.87%)	14 (13.08%)	0.89	0.35
Froth	7 (7.87%)	9 (8.41%)	0.00	>0.99

Internet has made it easier for all generations to access information, which may have made it difficult to see differences in knowledge.

Our analysis using the K.H. coder on open-ended responses revealed that respondents who had seen seizures made more references to "froth"; respondents who learned or heard about epilepsy in school made more references to "seizure." Respondents who learned about epilepsy through family or friends made fewer references to "consciousness." More to the term "Faint," These results indicated that people who have observed epileptic seizures in reality or know someone close to them with epilepsy has a deep impression of "seizures," "Faint," and "froth." This result suggests that the general public's image of epileptic seizures is that of blow foam from the mouth and fainting. On the contrary, people who learned about epilepsy via newspapers or TV had a deep impression of losing consciousness. A survey of Japanese medical students examined students' impressions of epilepsy before and after mass media coverage of a traffic accident in 2011. The association between the words "epilepsy" and "danger" was more robust in 2013 compared with that in 2010; however, the association was weaker in 2016 compared with that in 2013 [15]. Another previous study suggested that media coverage in 2015 was less influential than media coverage in 2011 and 2012 [25]. Our survey revealed no significant differences in knowledge about epilepsy among different age groups. Comparing our findings with previous surveys, we found that in 2021, 10 years after 2011, the perceived association between danger and epilepsy was less prevalent. However, the impression of the association between epilepsy and losing consciousness was more vital.

Respondents with higher EKS scores referenced "occur" and "brain." Respondents with sustainable knowledge about epilepsy were aware that epilepsy is a "brain" disease, and those who had learned about it at school were aware that epilepsy is a disease that causes "seizures." These results suggest that if a person has had some knowledge about epilepsy, he or she is likely to have correct knowledge about epilepsy.

Regarding demographic variables, the results showed that the word "illness" in living style was mentioned significantly more often in the single-resident group than in the cohabitant group. Although a detailed analysis of this result is complex because the respondents were not asked why they were living alone, they may have limited opportunities to learn about epilepsy due to insufficient communication with other people. Additionally, respondents who lived alone were more likely to view epilepsy as an "illness" rather than thinking about specific epilepsy symptoms.

4.2. What can we do to disseminate accurate knowledge about epilepsy?

Our findings indicated that the general public in Japan lacks accurate knowledge about epilepsy and that "seizure," "suddenly," "consciousness," "occur," and "lose" were the most common terms associated with respondents' impressions of epilepsy. Below, we discuss potential approaches for disseminating accurate knowledge about epilepsy among the general public in the future.

A cross-sectional study of university students in Yemen reported that approximately 23% of students believed epilepsy was a form of insanity, and 18% thought it was a form of mental retardation [26]. In addition, 57.5% of a Libyan survey sample considered epilepsy a mental disorder [27]. Epilepsy is perceived as a stigmatized health condition in developing countries [28]. In the current sample of the general public in

Japan, although there was a low level of accurate knowledge about epilepsy, there were four statements about "mental illness" concerning perceptions of epilepsy on the open-ended question. Furthermore, 54.93% of respondents selected the question item "epilepsy is a mental illness" on the EKS. Our respondents were aware that epilepsy is a disease that causes sudden seizures and loss of consciousness but did not have a thorough understanding of the characteristics of the disease and the mechanisms that cause it. In Japan, precisely as epilepsy is classified as a mental disorder in administrative divisions, more than half of the general public without epilepsy consider it a mental disorder.

Further education is still required to disseminate accurate knowledge of epilepsy among the general public. Japan initiated lectures on mental disorders in high school health and physical education classes in 2022. However, the curriculum excluded epilepsy in school education in Japan. If a classmate or teacher at school has epilepsy, students may have an opportunity to learn about the disease. Additionally, it might be beneficial to provide opportunities for students to learn more comprehensively about its characteristics and mechanisms in the school curriculum. In recent years, telemedicine and remote consulting have become popular due to the spread of the Internet to the general public. Reports from other countries have pointed to regional differences in telemedicine [29], but in Japan, there is no difference in Internet penetration rate across the country. We believe that telemedicine technology might be helpful in epilepsy-related education as well.

Epilepsy is a chronic disease of the brain. A systematic review of health literacy for chronic diseases indicates that interventions that optimize health literacy are essential for improving health status in chronic diseases [30]. There are limited reports of high-quality intervention studies related to epilepsy education in Japan. We believe that these studies should be conducted in the future to improve health literacy in epilepsy and disseminate accurate knowledge about the disease.

4.3. Limitations

As a potential limitation, our study was conducted among people registered with a specific online survey company. The sample was not representative of the general public and was restricted to individuals with a high affinity for the Internet. Our findings thus are hard to represent the entire Japanese society throughout this research.

5. Conclusions

The current study identified the level of knowledge and perceptions of epilepsy among the general public in Japan in 2021. By analyzing qualitative aspects of open-ended text responses, we successfully gathered evidence that might be useful for informing initiatives to provide accurate information about epilepsy to the public in the future. Medical experts are responsible for treating epilepsy to deliver accurate information to patients and, furthermore, society as a whole and to foster an environment where people with epilepsy can live without suffering from inconvenience or discrimination. We believe that one of the essential challenges for the future is to disseminate accurate information about epilepsy to the general public using the information comprehended this time.

Appendix

Appendix 1. Comparison by age groups (N = 213).

Frequent words (top 10)	Frequency (%)				X^2	P
	I: under 39 (N = 40)	II: 40–49 (N = 59)	III: 50–59 (N = 62)	IV: above 60 (N = 52)		
Seizure	14 (35.00%)	18 (30.51%)	22 (35.48%)	18 (34.62%)	0.41	0.94
Suddenly	9 (22.50%)	23 (38.98%)	19 (30.65%)	9 (17.31%)	7.27	0.06
Consciousness	8 (20.00%)	14 (23.73%)	18 (29.03%)	15 (28.85%)	1.43	0.70
Occur	7 (17.50%)	16 (27.12%)	17 (27.42%)	14 (26.92%)	1.61	0.66
Lose	7 (17.50%)	12 (20.34%)	15 (24.19%)	12 (23.08%)	0.77	0.86
Convulsions	6 (15.00%)	9 (15.25%)	14 (22.58%)	11 (21.15%)	1.64	0.65
Illness	7 (17.50%)	10 (16.95%)	9 (14.52%)	6 (11.54%)	0.87	0.83

(continued)

Frequent words (top 10)	Frequency (%)				X^2	P
	I: under 39 (N = 40)	II: 40–49 (N = 59)	III: 50–59 (N = 62)	IV: above 60 (N = 52)		
Brain	6 (15.00%)	6 (10.17%)	8 (12.90%)	6 (11.54%)	0.57	0.90
Faint	3 (7.50%)	9 (15.25%)	4 (6.45%)	5 (9.62%)	3.00	0.39
Froth	1 (2.50%)	6 (10.17%)	7 (11.29%)	4 (7.69%)	2.74	0.43

Appendix 2. Comparison by gender (N = 212).

Frequent words (top 10)	Frequency (%)		X^2	P
	Male (N = 115)	Female (N = 97)		
Seizure	38 (33.04%)	34 (35.05%)	0.03	0.87
Suddenly	28 (24.35%)	32 (32.99%)	1.53	0.22
Consciousness	28 (24.35%)	27 (27.84%)	0.18	0.67
Occur	23 (20.00%)	31 (31.96%)	3.36	0.07
Lose	26 (22.61%)	20 (20.62%)	0.03	0.85
Convulsions	21 (18.26%)	19 (19.59%)	0.01	0.94
Illness	18 (15.65%)	14 (14.43%)	0.00	0.96
Brain	13 (11.30%)	13 (13.40%)	0.06	0.80
Faint	7 (6.09%)	14 (14.43%)	3.23	0.07
Froth	10 (8.70%)	8 (8.25%)	0.00	>0.99

Appendix 3. Comparison by employment status (N = 213).

Frequent words (top 10)	Frequency (%)		X^2	P
	Employed (N = 150)	Unemployed (N = 63)		
Seizure	54 (36.00%)	18 (28.57%)	0.79	0.37
Suddenly	43 (28.67%)	17 (26.98%)	0.01	0.93
Consciousness	42 (28.00%)	13 (20.63%)	0.90	0.34
Occur	40 (26.67%)	14 (22.22%)	0.26	0.61
Lose	38 (25.33%)	8 (12.70%)	3.47	0.06
Convulsions	27 (18.00%)	13 (20.63%)	0.07	0.80
Illness	24 (16.00%)	8 (12.70%)	0.16	0.69
Brain	18 (12.00%)	8 (12.70%)	0.00	>0.99
Faint	11 (7.33%)	10 (15.87%)	2.74	0.10
Froth	9 (6.00%)	9 (14.29%)	2.94	0.09

Appendix 4. Comparison by the source of information about epilepsy (on the Internet) (N = 196).

Frequent words (top 10)	Frequency (%)		X^2	P
	Internet (N = 89)	out of Interne (N = 107)		
Seizure	7 (23.33%)	64 (38.55%)	1.93	0.16
Suddenly	6 (20.00%)	52 (31.33%)	1.07	0.30
Consciousness	6 (20.00%)	45 (27.11%)	0.35	0.55
Occur	9 (30.00%)	45 (27.11%)	0.01	0.92
Lose	4 (13.33%)	38 (22.89%)	0.87	0.35
Convulsions	9 (30.00%)	31 (18.67%)	1.37	0.24
Illness	3 (10.00%)	27 (16.27%)	0.36	0.55
Brain	3 (10.00%)	22 (13.25%)	0.04	0.85
Faint	3 (10.00%)	18 (10.84%)	0.00	>0.99
Froth	1 (3.33%)	15 (9.04%)	0.47	0.49

Appendix 5. Questionnaire content for the public.(Japanese and English versions).

	Japanese version	English version
Q1.	あなたの性別をお答えください。 1）. 男性 2）. 女性 3）. その他	Please indicate your gender. 1). Male 2). Female 3). Other
Q2.	あなたの年齢をお答えください。	Please indicate your age.
Q3.	あなたは現在「てんかん」をお持ちですか。 1）. 持っている 2）. 持っていない	Do you have epilepsy? 1). Yes 2). No
Q4.	あなたの最終学歴をお答えください。 1）. 卒業中学校 2）. 卒業高校 3）. 卒業専門学校 4）. 卒業短大・大学 5）. 在学中高校 6）. 在学中専門学校 7）. 在学中短大・大学 8）. 答えたくない	Please indicate your last level of education. 1). Graduated from junior high school 2). Graduated high school 3). Graduated vocational school 4). Graduated junior college/university 5). Currently enrolled in high school 6). Currently enrolled in Vocational School 7). Currently enrolled in College/University 8) Do not want to answer
Q5.	前問で[Q4]に在学中とお答えの方にお伺いします。 あなたの学年をお答えください。 ※1～6の数字でお答えください。	We would like to ask those who answered "currently enrolled in school" in [Q4]. Please indicate your grade. Please answer with a number from 1 to 6.
Q6.	あなたの現在の職業をお答えください。複数あてはまる方はもっともあてはまるものをお答えください。 1）. 学生 2）. 就労中 3）. 無職 4）. 休職中 5）. その他	Please tell us your current occupation. If more than one answer applies, please choose the one that applies best. 1). Student 2). Employed 3). Unemployed 4). Laid off 5). Other
Q7.	あなたの現在の同居の状態についてお答えください。 1）. 単身（1人暮らし） 2）. 家族（パートナー）と同居 3）. その他	Please answer the following questions about your current living situation. 1). Live alone 2). Living with family (partner) 3). Other
Q8.	「てんかん」という病気を聞いたことがありますか 1）. はい 2）. いいえ	Have you ever heard of the disease epilepsy? 1). Yes 2). No
Q9.	「てんかん」をどこで知りましたか 1）. 学校 2）. 家族・友人から聞いた 3）. テレビ・新聞 4）. インターネット 5）. その他	Where did you hear about epilepsy? 1). School 2). From a family member or friend 3). TV/newspaper 4). Internet 5). Other
Q10.	てんかん発作を見たことはありますか 1）. はい 2）. いいえ	Have you ever seen an epileptic seizure? 1). Yes 2). No
Q11.	「てんかん」とは、どのような病気だと思いますか 「てんかん」をご存じない方は、イメージでお答えください。	What kind of disease do you think epilepsy is? If you do not know, please describe epilepsy in your words.
Q12.	家族に「てんかん」を持っている人はいますか 1）. はい 2）. いいえ	Do you have family members with epilepsy? 1). Yes 2). No
Q13	てんかんの知識スケール（18項目）（Table 3）	The Epilepsy Knowledge Scale (18 items) (Table 3)

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