



Research article

Four questions to assess attitudes toward epilepsy, the caveness questions: Analytical study to verify the usefulness of the Japanese version

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ABSTRACT

Objective: This study sought to translate the Caveness questions (CQs), initially formulated in the United States for assessing attitudes toward people with epilepsy (PWE), into Japanese. Concurrently, the study examined the translated instrument's psychometric properties, specifically the usefulness within Japan's cultural and linguistic context.

Methods: We crafted the Japanese version of CQs-J by drawing upon the original English and German versions. Subsequently, On May 22nd and 23rd, 2023, we administered an online questionnaire survey to the general public registered with the online research survey service (Cross Marketing Group Inc., Tokyo, Japan). Inclusion criteria comprised an age of ≥ 18 years, processing proficient reading and speaking skills in Japanese, and demonstrating the ability to comprehend the Japanese questionnaires. In addition, we included questions about age, gender, education levels, employment status, and any experiences with epilepsy.

Results: A cohort comprising 400 ordinary people processing prior exposure to information regarding epilepsy participated in the study. Participants provided informed consent before proceeding to complete the study questionnaire. The CQs-J, encompassing following four items. CQ1) Would you object to having any of your children in school or at play associate with persons who sometimes had seizures (fits)?

CQ2) Do you think epilepsy is a form of insanity or not?

CQ3) Do you think epileptics should or should not be employed in jobs like other people?

CQ4) Would you object to having a son or daughter of yours marry a person who sometimes has seizures (fits)?

We compared CQs-J groups with negative or positive attitudes towards epilepsy, taking into account age, gender, employment status, education levels, and knowledge and experiences of the condition. Those who responded to the CQ1 question that they would object to their child's occasional association with someone at school or at play who has seizures (fits) were significantly more negative in their experiences with epilepsy: they did not understand what to do during seizures (Ex3, $p < 0.01$), and they did not believe in the effectiveness of epilepsy treatment (Ex4, $p < 0.01$). In addition, males were significantly more likely to respond that epilepsy is insanity when asked the CQ2 question ($p < 0.001$). Additionally, in CQ3, do you think people with

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epilepsy should have the same access to jobs as other people with epilepsy? Significant differences were found for younger age, a lower overall Epilepsy Knowledge Scale score ($p < 0.001$), being employed ($p = 0.028$), Ex3 ($p = 0.041$), and Ex4 ($p < 0.01$). Finally, older people were significantly more opposed to marrying someone who has seizures in CQ4 ($p < 0.001$) or is not working, and others were also significantly more opposed ($p = 0.030$).

Significance: We evaluated the utility of the Japanese version of the CQs, demonstrating its effectiveness for assessing treatment strategies in stigma reduction and enabling cross-cultural comparisons of attitudes towards epilepsy. In large-scale social surveys, the CQs-J scale effectively captures broad attitudes toward epilepsy with a limited number of items and offers the advantage of ease of use for longitudinal studies, such as tracking changes in attitudes over time. Furthermore, we expect the CQs-J results to facilitate in-depth cross-cultural comparisons of attitudes toward epilepsy by comparing them across different cultures.

1. Introduction

Epilepsy-related stigma manifests ubiquitously across diverse cultural contexts [1,2], signifying its status as a paramount concern for individuals grappling with people with epilepsy (PWE) and their families [3,4]. Prejudices and attitudes toward epilepsy exhibit variability across regions and temporal epochs. Despite the capacity to examine attitudes toward epilepsy across distinct periods and geographical locations, multicultural comparative studies utilizing standardized questionnaires to explore attitudes toward epilepsy at various times and in different countries are notably limited.

Caveness et al. (1965, 1980) reported results from the American Institute of Public Opinion in thirty years of longitudinal responses to questions about epilepsy from representatives of the adult population in the United States [5,6]. In their study, Caveness et al. (1965, 1980) adopted four questions:

CQ1) Would you object to having any of your children in school or at play associate with persons who sometimes had seizures (fits)?

CQ2) Do you think epilepsy is a form of insanity or not?

CQ3) Do you think epileptics should or should not be employed in jobs like other people?

CQ4) Would you object to having a son or daughter of yours marry a person who sometimes has seizures (fits)?

The two ways to answer the CQs are "yes" or "no." Caveness et al. (1980) survey analyzed responses to these four questions and found that negative responses to PWE decreased proportionally with age. The findings indicated that individuals with higher education, higher employment, younger age groups, and urban areas in the United States manifest the most favorable attitudes [6]. As documented in previous studies, the CQs have also been deployed in various countries [7–10]. Notably, representative surveys of attitudes toward epilepsy in Germany spanning 1967 and 2008 employed the CQs instrument between 1949 and 1980 [10]. The prevalence of discernible discrimination against PWE is particularly notable in specific regions, notably Japan [11,12]. It is noteworthy that longitudinal studies employing consistent questions over successive periods, comparable to the structure of the CQs, are notably lacking in the current body of research.

Our study endeavored to translate the CQs, initially developed in the United States, into Japanese. Subsequently, our focus encompassed evaluating its usefulness in assessing attitudes towards PWE within the Japanese cultural context.

2. Methods

2.1. Participants and procedure

Employing an online questionnaire, we surveyed the ordinary public registered with an online research survey service provided by Cross Marketing Group Inc., Tokyo, Japan. This study collected responses from people with no epilepsy across all regions of Japan. Initial inquiries involved ascertaining participants' familiarity with or exposure to information about epilepsy, with subsequent questions directed exclusively to those affirming such awareness. The data collection occurred on May 22nd and 23rd, 2023, with a cohort of 400 individuals contributing to completing the questionnaire during this specified period.

2.2. Measurements

2.2.1. Sociodemographic data

We systematically instructed participants to complete the questionnaire, eliciting information about age, gender, living region, employment status, and education level. This method facilitated a comprehensive characterization of the study cohort.

2.2.2. Development of the Japanese version of the Caveness questions (CQs-J)

The original Caveness questions have four items. Following the Principles of Good Practice Translation and Cultural Adaptation of Patient-Reported Outcomes Measures, we translated the English and German versions of the CQs into a Japanese version (CQs-J). Guided by these principles, the overarching objective was to develop a culturally sensitive version of the scale equivalent to the original in the following aspects: item, semantic, and operational and measurement equivalence. The integrated form was back-translated into Japanese and English by two independent translators and combined into one back-translation. We compared the

back-translation with the original CQs. Differences were highlighted and discussed by an expert group. This panel comprised a German neurologist, a German sociologist, two Japanese neuropsychiatrists, and three psychologists (one German and two Japanese). Following comprehensive deliberations, we made adjustments to ensure consistency in the concepts between the original and the translations, culminating in developing the CQs-J. For the pretesting phase of the questionnaire, we engaged a cohort at Saitama Medical Center comprising ten individuals proficient in the Japanese language. Their assignment involved responding to the questionnaire and providing assessments of its comprehensibility. Finally, we conducted an expert group meeting to evaluate the content and face validity of the translated versions, the results of the pretesting, and the equivalence with the original scale. Specifically, the focus was on each item's conceptual, semantic, and normative equivalence. Notably, the CQs-J comprises four distinct items (Supporting Table 1).

2.2.3. Personal experience with people with epilepsy and seizure

We also asked participants' personal epilepsy experience, which was assessed by the following questions.

- Ex1.** Have you ever witnessed a seizure?
Ex2. Have you ever personally known someone with epilepsy?
Ex3. Would you know what to do if someone has an epileptic seizure?
Ex4. Can epilepsy be treated successfully?

The survey on public attitudes toward epilepsy by Caviness in 1949 [5,6] had previously introduced Questions Ex1 and Ex2. We added questions Ex3 and Ex4 [6,13] as potential predictors of attitudes toward PWE, similar to Thorbecke and May et al. [10,14]. We also translated this questionnaire from German to Japanese, similar to the procedure used to create the CQs-J in 2.2.2, and created a Japanese version (Supporting Table S2). The answer options for Ex1-3 questions are yes or no. In addition, Ex4 questions have yes, no, or I do not know options.

2.2.4. The epilepsy knowledge Scale 27 items

Following most studies on attitudes toward PWE [10,14–16], we included a scale of knowledge about epilepsy. The Epilepsy Knowledge Scale encompasses three subscales: Causes, Symptoms, and Treatment of epilepsy. The scale comprises 27 true or false items (answer options: yes, no, I do not know). The Epilepsy Knowledge (total) score was reported as the percentage of items answered correctly. We also translated this questionnaire from German to Japanese, the same as the procedure used to create the CQs-J in 2.2.2, and created a Japanese version (Supporting Table S3).

2.3. Ethical considerations

This research was implemented under the approval of the Research Ethics Committee of Saitama Medical Center, Saitama Medical University (No. 2023-025) and supported by JSPS KAKENHI Grant Number JP21K13709 and a research grant of the Japan Epilepsy Research Foundation (JERF). 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. Statistical analyses

We presented descriptive statistics as frequencies, mean \pm standard deviation (S.D.) for continuous and percentages for categorical variables. Additionally, we classified the cohort into two groups based on their responses (yes or no) to CQ1), CQ2), CQ3), and CQ4). We compared age, gender, employment status, educational level (low, medium, high), total score on the epilepsy knowledge scale, and

Table 1
Sociodemographic characteristics (n = 400).

		General public in Japan (n = 400)	
		n	%
Gender	male	182	45.5 %
	female	218	54.5 %
Age	mean \pm SD	53.18 \pm 16.73 (18–83)	
Education ^a	low	13	3.3 %
	medium	205	51.3 %
	high	182	45.5 %
Employment	employed	203	32.3 %
	unemployed	40	10.0 %
	Housewife/Househusband	84	21.0 %
	Student	12	3.0 %
	Other/Retired.	61	15.3 %

^a Education: low (9 years, Elementary School and Junior high school, compulsory education in Japan), medium (12–14 years, High school, vocational school, junior college), high (over 16 years, undergraduate, graduate (master, and doctoral) programs).

Table 2

The personal experience with people with epilepsy and seizures (n = 400).

		n	%
Ex1. Have you ever personally known someone with epilepsy?	yes	137	34.3 %
	no	263	65.8 %
Ex2. Have you ever witnessed a seizure?	yes	125	31.3 %
	no	275	68.8 %
Ex3. Do you know what you should do when someone has an epileptic seizure?	yes	106	26.5 %
	no	294	73.5 %
Ex4. In your opinion, is it correct that epilepsy can be treated successfully?	yes	141	35.3 %
	no	18	4.5 %
	do not know	241	60.3 %

epilepsy experiences (Ex1, Ex2, Ex3, Ex4) between these groups. For the continuous variables of age and total score on the epilepsy knowledge scale, we used the *t*-test. For the categorical variables of gender, employment status, educational background, and epilepsy experiences (Ex1, Ex2, Ex3, Ex4), we used the chi-square test. When the chi-square test results were significant, adjusted residuals were used for group comparisons.

We used SPSS ver. 29.0 (IBM, Inc., NY, USA) for statistical analysis, with a less than 5 % significance level.

3. RESULTS

3.1. Participants' characteristics and experiences with epilepsy

The study cohort comprised 400 general public (182 males, 218 females; mean age 53.18 ± 16.73). Table 1 outlines socio-demographic characteristics. All respondents were aware of epilepsy. However, individuals who had witnessed an epileptic seizure constituted 31.3 % of the sample. Table 2 demonstrates the respondents' personal experiences with epilepsy and seizures.

3.2. Sufficient knowledge of epilepsy from epilepsy knowledge Scale (EKS) score

The results of the Epilepsy Knowledge Scale (EKS) showed a total mean score of 38.18 (SD 20.43) points on a 100-point scale. The results for each factor were 1. Cause: 44.69 (SD 29.71), 2. Symptoms: 44.53 (SD 24.7), and 3. Treatment: 25.33(SD 22.12).

3.3. Comparison of CQs-J responses with background factors, knowledge and experience of epilepsy

We present the results of the responses to the Caveness question, comprising four questions, in Table 3.

We classified participants into two groups based on their responses (yes or no) to each item (CQ1-4). Between these groups, we compared age, gender, employment status, educational level, total score on the epilepsy knowledge scale, and epilepsy-related four experiences (Ex1-4). Table 4 compares age and EKS scores by response to the CQs 1–4 (yes or no). Table 5 compares gender, employment status, education level, and epilepsy experience by response to the CQs 1–4 (yes or no). Those who responded affirmatively to the CQ1 showed significant differences in epilepsy-related experiences, specifically in knowing what to do during a seizure (Ex3) and believing in the success of epilepsy treatment (Ex4). In CQ2, a significantly higher proportion of males said they thought epilepsy was a form of insanity. ($p < 0.001$). Furthermore, we observed significant differences between the two groups in terms of age, total epilepsy knowledge scale score, employment status, Ex3, and Ex4. Compared to the group that answered "no" to CQ3, the group that answered "yes" was significantly older ($p < 0.001$), had a significantly higher total epilepsy knowledge scale score ($p = 0.013$), had a significantly lower proportion of individuals who were employed ($p = 0.028$), had a significantly higher proportion of individuals who answered "yes" to Ex3 ($p = 0.041$), and had a significantly higher proportion of individuals who answered "yes" to Ex4 and a lower proportion who answered "do not know" to Ex4 ($p = 0.002$). For CQ4, the group that answered "yes" was significantly older compared to the group that answered "no" ($p < 0.001$). In addition, they had a significantly higher proportion of individuals who reported "other"

Table 3

The results of CQs (n = 400).

		n	%
CQ1. Would you object to having any of your children in school or at play associate with persons who sometimes have seizures?	yes	156	39.0 %
	no	244	61.0 %
CQ2. Do you think epilepsy is a form of insanity?	yes	113	28.3 %
	no	287	71.8 %
CQ3. Do you think people with epilepsy should be employed in jobs like other people?	yes	250	62.5 %
	no	150	37.5 %
CQ4. Would you object to having a son or a daughter of yours marry a person who sometimes has seizures?	yes	170	42.5 %
	no	230	57.5 %

Negative attitudes are marked in bold.

Table 4
Comparison of CQ responses with age and knowledge of epilepsy (EKS scores).

	Mean	SD	Median	Mean	SD	Median	p
CQ1)	No (n = 244)			Yes (n=156)			
Age	52.85	16.94	54.00	53.69	16.50	53.50	0.700
EKS	38.93	19.29	40.74	36.99	22.18	40.74	0.413
CQ2)	No (n = 287)			Yes (n=113)			
Age	53.22	16.36	53.00	53.07	17.79	54.00	0.952
EKS	37.36	20.00	40.74	40.25	21.54	40.74	0.204
CQ3)	No (n=230)			Yes (n = 170)			
Age	49.51	16.52	47.00	55.38	16.53	56.00	0.001 ^b
EKS	34.54	21.91	37.04	40.36	19.25	40.74	0.013 ^a
CQ4)	No (n = 150)			Yes (n=250)			
Age	50.35	16.74	49.00	57.01	16.04	60.00	0.001 ^b
EKS	37.05	20.53	40.74	39.69	20.32	40.74	0.214

Abbreviations: CQ: Caviness questions, EKS: Epilepsy Knowledge Scale total score.

Negative attitudes are marked in bold.

^a P < 0.01.

^b P < 0.001.

employment status compared to the group that answered "no" (p = 0.030).

4. Discussions

We substantiated the usefulness of the CQs-J through correlations with other relevant factors. The CQs-J 1–4 are independent measures of attitude toward epilepsy. We propose an in-depth consideration of its integration with other scales for a more comprehensive understanding of attitudes toward epilepsy.

Nagamori et al. (2018) found that participants with experience of epilepsy had higher levels of knowledge about epilepsy in Japan between 2013 and 2017. In their survey, the question of experience with epilepsy asked whether the participants knew anyone with epilepsy [17]. This question's answer was about 48 % in Russia [18], 40 % in Austria [19], 55 % in South Korea [20], 19 % in Thailand [21], and Nagamori et al. from Japan reported that 18 % (2013) and 16 % (2017) knew someone with epilepsy personally. In our survey in 2023, the number of people who knew someone with epilepsy was 34.3 %. According to international studies, the point prevalence of active epilepsy is 6.38 per 1000 persons, while the lifetime prevalence is 7.60 per 1000 persons [22]. While the prevalence of PWE has not manifested a notable increase over the past decade, the rise in the number of people acquainted with someone diagnosed with epilepsy personally may be attributed to an elevated trend in individuals voluntarily disclosing their epilepsy diagnosis in Japan. However, it would be necessary to survey PWE to assess the extent to which people with epilepsy disclose their epilepsy at their places of employment and schools. In a nationwide survey of PWE conducted by Kuramochi et al. (2022), 19.7 % said they had never disclosed their disease (epilepsy) to others. The reasons given included reluctance to reveal their health condition publicly, resistance to participation due to potential prejudice, and potential damage to their self-esteem [23].

The lack of significant differences observed in Japan between educational levels for each of the CQs-J 1–4 scores was contrary to the expectations derived from previous research in other countries. In Japan, the negative attitudes towards epilepsy may not differ by the level of education, as the educational reforms implemented after World War II ensured that more than 90 % of the population attained a similar average level of education. Those with more accurate knowledge on the Epilepsy Knowledge Scale, on the other hand, held more positive views about epilepsy: they believed that people with epilepsy should work alongside the general population (CQ3), and they did not oppose children marrying people with epilepsy (CQ4). These results suggested that society could disseminate correct knowledge about epilepsy to reduce negative attitudes toward epilepsy. In addition, employment status was likewise associated with positive attitudes toward epilepsy. A report from Japan in 2021 by the authors identified a significant difference in epilepsy knowledge based on employment status, suggesting that individuals with more social interaction opportunities are more likely to learn or hear about epilepsy [12].

The only difference in attitudes toward epilepsy that differed by gender was in CQ2, which asked, Do you think epilepsy is a form of insanity or not? Epilepsy is sometimes classified as a psychiatric disorder in Japan, especially PWE seeking welfare assistance are required to procure a mental disability certificate. Since gender differences in negative attitudes toward epilepsy have not been consistent in previous reports, more detailed examination of the individual's background will be necessary.

In order to mitigate stigma and enhance the quality of life for PWE, it is imperative to offer comprehensive epilepsy treatment while disseminating accurate information about epilepsy to the general populace. "Month of Epilepsy," which originated in 1983 as a means to bolster awareness-raising endeavors linked to epilepsy, aims to heighten nationwide understanding of the condition. The 2013 statement by the Japan Epilepsy Association included the following goals: promote social integration and eliminate discrimination against epilepsy; promote social integration and eliminate discrimination against epilepsy in life in general, especially in work, school, and mobility; encourage educational activities to help all people understand epilepsy and eliminate prejudice and bias; encourage

Table 5
Comparison of CQ responses with gender, employment status, education level, and experiences of epilepsy.

			CQ ^a 1			CQ2			CQ3			CQ4		
			no	yes	p	no	yes	p	no	yes	p	no	yes	p
gender	male	n	107	75	0.408	112	70	0.000 ⁱ	75	107	0.162	113	69	0.090
		%	43.9	48.1		39.0	61.9		50.0	42.8		49.1	40.6	
		%	%	%		%	%		%	%				
	female	n	137	81		175	43		75	143		117	101	
		%	56.1	51.9		61.0	38.1		50.0	57.2		50.9	59.4	
		%	%	%		%	%		%	%				
employment status	employed	n	121	82	0.602	144	59	0.363	89	114	0.028 ^g	126	77	0.030 ^g
		%	49.6	52.6		50.2	52.2		59.3	45.6		54.8	45.3	
		%	%	%		%	%		%	%				
	unemployed	n	59	31		61	29		27	63		54	36	
		%	24.2	19.9		21.3	25.7		18.0	25.2		23.5	21.2	
		%	%	%		%	%		%	%				
	other	n	64	43		82	25		34	73		50	57	
		%	26.2	27.6		28.6	22.1		22.7	29.2		21.7	33.5	
		%	%	%		%	%		%	%				
education level ^b	low + middle	n	132	86	0.840	163	55	0.142	73	145	0.070	129	89	0.458
		%	54.1	55.1		56.8	48.7		48.7	58.0		56.1	52.4	
		%	%	%		%	%		%	%				
	high	n	112	70		124	58		77	105		101	81	
		%	45.9	44.9		43.2	51.3		51.3	42.0		43.9	47.6	
		%	%	%		%	%		%	%				
Ex1 ^c	yes	n	91	46	0.108	101	36	0.527	43	94	0.068	83	54	0.368
		%	37.3	29.5		35.2	31.9		28.7	37.6		36.1	31.8	
		%	%	%		%	%		%	%				
	no	n	153	110		186	77		107	156		147	116	
		%	62.7	70.5		64.8	68.1		71.3	62.4		63.9	68.2	
		%	%	%		%	%		%	%				
Ex2 ^d	yes	n	81	44	0.293	89	36	0.869	39	86	0.079	69	56	0.530
		%	33.2	28.2		31.0	31.9		26.0	34.4		30.0	32.9	
		%	%	%		%	%		%	%				
	no	n	163	112		198	77		111	164		161	114	
		%	66.8	71.8		69.0	68.1		74.0	65.6		70.0	67.1	
		%	%	%		%	%		%	%				
Ex3 ^e	yes	n	78	28	0.002 ^h	75	31	0.791	31	75	0.041 ^g	64	42	0.485
		%	32.0	17.9		26.1	27.4		20.7	30.0		27.8	24.7	
		%	%	%		%	%		%	%				
	no	n	166	128		212	82		119	175		166	128	
		%	68.0	82.1		73.9	72.6		79.3	70.0		72.2	75.3	
		%	%	%		%	%		%	%				
Ex4 ^f	yes	n	100	41	0.004 ^h	101	40	0.283	37	104	0.002 ^h	88	53	0.125
		%	41.0	26.3		35.2	35.4		24.7	41.6		38.3	31.2	
		%	%	%		%	%		%	%				
	no	n	7	11		10	8		10	8		7	11	
		%	2.9	7.1		3.5	7.1		6.7	3.2		3.0	6.5	
		%	%	%		%	%		%	%				
do not know	n	137	104		176	65		103	138		135	106		
	%	56.1	66.7		61.3	57.5		68.7	55.2		58.7	62.4		
	%	%	%		%	%		%	%					

Negative attitudes are marked in bold.

^a Caveness questions

^b Education level: low (9 years, Elementary School and Junior high school, compulsory education in Japan), medium (12–14 years, High school, vocational school, junior college), high (over 16 years, undergraduate, graduate (master, and doctoral) programs).

^c Ex1. Have you ever witnessed a seizure?.

^d Ex2. Have you ever personally known someone with epilepsy?.

^e Ex3. Would you know what to do if someone has an epileptic seizure?.

^f Ex4. Can epilepsy be treated successfully?.

^g P < 0.05,.

^h P < 0.01.

ⁱ P < 0.001.

educational activities to help all people understand seizures and eliminate prejudice and bias. The percentage of people who consider epilepsy a psychiatric disorder (CQ2) was about 24 % in Russia [18], 11 % in Austria [19], 34 % in South Korea [20], 32 % in Thailand [21], 6.7 % in Germany [10], 13 % in Japan [17]. Our study unveiled an increase of 28.3 % in Japan. These outcomes indicate an inadequate dissemination of correct knowledge about epilepsy spanning the decade since 2013. However, Japan introduced groundbreaking legislation in April 2016, prohibiting discrimination against individuals with disabilities, including epilepsy. Based on these historical efforts and our findings, we posit a necessity for establishing a forum aimed at enhancing public education on epilepsy and disseminating pertinent information about the condition.

As for questions related to epilepsy, as it relates to family members (CQ1), 39.0 % of respondents in Japan were resistant to their children having contact with someone with epilepsy, and 11.4 % in Germany [10]. In addition, 23.8 % of respondents in Germany [10] and 42.5 % in Japan agreed with the question, "I am against marrying a person whose children can have epileptic seizures" (CQ4). The observed trend indicates an increasing resistance or opposition towards individuals with epilepsy within Japan. In Japan, one possible cause of prejudice against epilepsy could be the negative connotations associated with the Japanese term for epilepsy, "tenkan", which conveys meanings such as "madness" or "volatile temperament prone to obsession." However, the etymology of epilepsy in Western culture also traces back to the verbs "catching" and "attacking," with its prefix "epi" indicating that the action is directed towards another person or force. In other words, etymologically, it suggests that another person or force is exerting its action on oneself, thereby implying a lack of control over the phenomenon. The difference in prejudice against epilepsy between Western cultures and Japan also suggests the subtle influence of differences in the etymology of the term. However, it will be necessary to investigate in future studies the extent of knowledge regarding the etymology of the term in each cultural context.

Should PWE be treated in the same work framework (e.g., employment, working conditions, job description) as people without epilepsy in terms of employment? (CQ3), 62.5 % in Japan and 86.0 % in Germany agreed. In Japan, PWE may experience social alienation from apprehensions of prejudice and the imperative to conceal their condition. This cultural phenomenon may have the potential to engender deleterious consequences, including depression, diminished self-esteem, and heightened stigmatization. On the other hand, in Germany, which has well-developed epilepsy legislation and fewer obstacles in daily life compared to Japan, PWE may encounter fewer impediments to disclosing their condition, especially in public spheres such as employment. Currently, Japan lacks a survey addressing the occupations of PWE in the ordinary population. Therefore, a compelling need arises for subsequent longitudinal inquiries to monitor potential changes in this domain over time systematically.

4.1. Limitations

A potential limitation of our study lies in its exclusive focus on individuals affiliated with a designated online survey company. Consequently, the sample cohort may not represent the general public as it inherently comprises individuals with a conspicuous proclivity for internet engagement. Hence, our findings from this study may be regarded as intricate, offering a perspective that reflects the characteristics of individuals within Japanese society who exhibit a heightened inclination towards online survey participation. Another possible limitation is self-selection bias. Because participants voluntarily participate in surveys, it is possible that people with particular interests or with particular positions may participate more frequently. This could bias the results toward the opinions and experiences of certain people. Furthermore, it cannot be completely ruled out that participants may misunderstand the questions or intentionally provide inaccurate information.

To counteract these issues, it is important to make the sample as homogeneous as possible at the time of registration with the online survey company. It was also important to ask for more detailed participant background information at the time of the next survey, such as where they were born and raised, where they currently live, their living environment, and whether they have a family history of epilepsy, although we did not do this survey at this time.

In the future, when we conduct surveys using our CQs-J, we will be able to combine other questionnaires and background information for further statistical analysis.

5. Conclusions

The findings demonstrate that the CQs-J is valuable for measuring attitudes toward PWE in Japanese society. Experience with epilepsy, sufficient knowledge about epilepsy, age, gender, and employment status are significantly associated with negative attitudes towards epilepsy. In large-scale social surveys, the CQs-J scale effectively captures broad attitudes toward epilepsy with a limited number of items and offers the advantage of ease of use for longitudinal studies, such as tracking changes in attitudes over time. Furthermore, we expect the CQs-J results to facilitate in-depth cross-cultural comparisons of attitudes toward epilepsy by comparing them across different cultures.

Future research on stigma toward conversion may include the need for longitudinal studies to track changes in attitudes over time using the CQs-J created in this study. Stigma is a concept that changes over time and in the social environment, suggesting that the results of the longitudinal study could be applied to future intervention research to reduce stigma toward epilepsy.

Data availability statement

Our research data has not been deposited into a publicly available repository. The authors have archived the raw data supporting the conclusions of this article. Due to confidentiality obligations, the data will not be made available to the general. If requested by other researchers, the authors will provide the data. Please contact the corresponding author if necessary.

Ethical publication statement

This study was conducted following the approval of the study protocol by the institutional review board of Saitama Medical Center, Saitama Medical University (approval No. 2023-025). 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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CRedit authorship contribution statement

Izumi Kuramochi: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Takayuki Iwayama:** Writing – review & editing, Validation, Software, Methodology, Formal analysis. **Takafumi Shiganami:** Writing – review & editing, Methodology. **Sayaka Kobayashi:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Haruo Yoshimasu:** Writing – review & editing, Supervision, Project administration, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.heliyon.2024.e35853>.

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