



## Public awareness and experiences associated with epilepsy in Japan, 2013–2017

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### ARTICLE INFO

#### Article history:

Received 18 February 2018

Revised 14 April 2018

Accepted 5 May 2018

Available online 13 July 2018

#### Keywords:

Epilepsy

Knowledge

Experience

Awareness

Public opinion in Japan

### ABSTRACT

**Background:** Public attitudes and stigma toward epilepsy may limit people with epilepsy (PWE) in seeking treatment and participating in social activities. The prevalence of epilepsy is approximately 0.8% in Japan, similar to rates reported in other countries. Although epilepsy is relatively common, few studies have investigated public awareness about epilepsy in Japan. Recently, several serious car accidents in Japan involving PWE resulted in pedestrian fatalities. Traffic accidents involving PWE have been reported extensively and repeatedly in the media since 2011. In 2013 and 2017, our research group conducted a large investigation of awareness about epilepsy targeting the general public. Previous studies have reported that knowledge is one of the factors involved in improving attitudes and reducing stigma. The aim of the current study was to compare survey results, especially regarding knowledge of epilepsy, and capture changes in public awareness between 2013 and 2017.

**Methods:** A total of 2160 people (1080 in each year) participated, with a total of 540 women in each year, aged 20–79 years. Participants lived in the greater Tokyo area as well as the Tohoku and Kansai regions of Japan. All participants answered survey questions online in January 2013 and April 2017. We analyzed five questions regarding the participants' demographic data, nine questions regarding knowledge about epilepsy, and five questions regarding experiences with epilepsy. For questions investigating the respondents' knowledge about epilepsy, we counted only the correct answers and scored these for each respondent.

**Results:** Knowledge scores decreased from 2013 to 2017, demonstrated by statistical analysis. However, the effect size was very small. Knowledge scores among the following groups were higher in both 2013 and 2017: people who had read or heard about epilepsy, those who had witnessed people having an epileptic seizure, people who had acquaintances who were PWE, those who had PWE in their family, and people who had studied medicine or worked in a medical profession.

**Conclusion:** We revealed that participants who had some experience with epilepsy had higher knowledge levels in both 2013 and 2017. This suggests that such experiences could be important for motivating people to seek appropriate and accurate knowledge about epilepsy, and could result in a reduction of stigma. Greater awareness is needed among the general public in Japan about various aspects of epilepsy.

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## 1. Introduction

Epilepsy is one of the most frequently occurring chronic neurological disorders internationally. In Japan, patients with epilepsy constitute approximately 0.8% of the total population, resulting in approximately one million people with epilepsy (PWE) in the country [1]. Epilepsy occurs not only among young children but also in adults and elderly individuals. Thus, epilepsy is a relatively common chronic disease in Japan, as in other countries.

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In 2011 and 2012, several serious car accidents in Japan caused by PWE resulted in fatalities that included children. These traffic accidents involving PWE were reported frequently in the media, and these tragedies had a palpable impact on Japanese society. In a previous study, we found that implicit stigmatizing attitudes were increased among medical students in 2013, just after the media coverage of the traffic accidents had sharply increased [2]. As a result, in 2014, two laws concerning PWE drivers were modified. The Japan Epilepsy Society and Japan Epilepsy Association advised clinicians, patients, and their families to review the content of these laws, and to obey them. Media coverage on this topic gradually decreased after 2014. The circumstances surrounding PWE have greatly changed in recent years, together with the recommendation of the World Health Organization to

address stigma toward epilepsy. However, there have been few studies of awareness about epilepsy among the general public in Japan.

Stigma is a global phenomenon associated with a range of chronic diseases, including epilepsy, that has great negative impacts on patients and their families and deleterious consequences for quality of life. Some of these effects include delayed diagnosis, risk behaviors, and poor adherence to treatment [3]. Many previous studies have shown that attitudes toward PWE are influenced by the degree of knowledge about the condition [4–7]. In 2013 and 2017, we conducted a large-scale study of awareness about epilepsy to reveal public attitudes toward and knowledge about epilepsy in Japan. We aimed to compare the results between 2013 and 2017 to determine the presence of any trends or large changes over time. We hypothesized that the public knowledge levels about epilepsy in 2017 would be higher than those in 2013 because there was less negative media coverage in 2017, and some awareness-raising activities were conducted in Japan.

## 2. Methods

### 2.1. Participants

A total of 2160 people (1080 in each year) participated in our investigation, with a total of 540 women in each year, aged 20–79 years. Participants lived in the greater Tokyo area (Ibaraki, Tochigi, Gunma,

Saitama, Chiba, Tokyo, and Kanagawa) or in the Tohoku (Aomori, Iwate, Miyagi, Akita, Yamagata, and Fukushima) or Kansai (Mie, Shiga, Kyoto, Osaka, Hyogo, Nara, and Wakayama) regions of Japan. In January 2013 and in April 2017, participants answered questions online, through a service provided by Rakuten Research Inc. All participants provided demographic information in advance when they registered at Rakuten Research Inc. and were paid 15 Rakuten points for completing each questionnaire. Rakuten Research Inc. randomly selected a sample of their members to receive e-mails linking to our survey from among those that were suitable for the needs of the study, based on the demographic information the company had already obtained. Participants were categorized by gender, age, and residence area (Table 1). Some participants who were interested in our investigation accessed and answered the questionnaire online after reading an explanation of this survey and agreeing to participate. A total of 14,769 emails were sent, with a total of 1300 responses in 2017. Rakuten Research Inc. stopped collecting data when the number of participants had reached the target, so we could not capture the overall response rate. Participants with incomplete and inappropriate answers were excluded. Thus, we obtained data from 1080 successive participants. This study was approved by the Ethics Committee of Tokyo Medical and Dental University (approval nos. 1403, M2016–305). All participants provided consent to participate in the study by clicking a button before beginning the questionnaire.

**Table 1**

Participants' demographic information and average knowledge scores regarding epilepsy, with significant effects of gender, age group, and educational background by p-value but enough effect size detected in only age group.

		2013		2017	
		Number(%)	Knowledge score (mean ± SE)	Number(%)	Knowledge score (mean ± SE)
<b>Gender</b>					
	Male	540 (50%)	4.5 ± 0.1	540 (50%)	4.1 ± 0.1
	Female	540 (50%)	4.6 ± 0.1	540 (50%)	4.5 ± 0.1
<b>Age</b>					
	20–49 y.o.	595 (F=293)	4.4 ± 0.1	573 (F=306)	4.0 ± 0.1
	50–79 y.o.	485 (F=247)	4.8 ± 0.1	507 (F=234)	4.7 ± 0.1
<b>Living area</b>					
	Kanto-region	360 (F=180)	4.7 ± 0.1	360 (F=180)	4.3 ± 0.1
	Kansai-region	360 (F=180)	4.4 ± 0.1	360 (F=180)	4.4 ± 0.1
	Tohoku-region	360 (F=180)	4.6 ± 0.1	360 (F=180)	4.3 ± 0.1
<b>Marital status</b>					
	Married	717 (66%)	4.6 ± 0.1	696 (64%)	4.4 ± 0.1
	Single	363 (34%)	4.5 ± 0.1	384 (36%)	4.2 ± 0.1
<b>Employment status</b>					
	Regular employment	401 (37%)	4.5 ± 0.1	451 (42%)	4.2 ± 0.1
	Non regular employment	194 (18%)	4.5 ± 0.2	185 (17%)	4.2 ± 0.3
	Self-own business	77 (7%)	4.4 ± 0.3	70 (6%)	4.5 ± 0.3
	Housemaker	224 (21%)	4.6 ± 0.2	200 (19%)	4.4 ± 0.2
	Others	184 (17%)	4.9 ± 0.2	163 (15%)	4.5 ± 0.2
<b>Educational background</b>					
	Junior high school	18 (2%)	4.7 ± 0.6	30 (3%)	3.6 ± 0.4
	High school	333 (31%)	4.3 ± 0.1	329 (31%)	4.1 ± 0.1
	College	261 (24%)	4.6 ± 0.1	247 (14%)	4.2 ± 0.2
	University	424 (39%)	4.8 ± 0.1	430 (39%)	4.5 ± 0.1
	Graduate school	44 (4%)	4.9 ± 0.4	44 (4%)	5.1 ± 0.4

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