A Survey of Epilepsy-related Knowledge, Attitudes and Practices of Home Healthcare Nurses in the San-in Region of Japan

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ABSTRACT

Background Comprehensive care is necessary for people with epilepsy (PWE) to lead a fulfilling life at home and in the community. The purpose of this study was to determine the epilepsy-related knowledge, attitudes and practices of home healthcare nurses (HHNs) in the San-in region of Japan.

Methods A questionnaire survey was conducted by mail of 546 HHNs working in Tottori and Shimane Prefectures. The questionnaire assessed the epilepsy-related knowledge, attitudes and practices of HHNs. For the analysis, simple and cross tabulation of questionnaire responses were conducted, and the chi-squared test was used for statistical testing.

Results A total of 285 HHNs participated in the study. Of the respondents, 43.9% had experience taking care of PWE in a home healthcare nursing setting. Regarding the cause of epilepsy, in descending order the percentage of correct responses were 86.7% for stroke, 85.3% for head injury, and only 13.3% for dementia. Concerning how to respond to an epileptic seizure, almost all respondents answered correctly, but 29.8% gave the incorrect answer of "place something inside the mouth." Regarding the practices of HHNs in relation to caring for PWE, nurses scored 52.0% for collaborating with the attending physician, indicating the need for improvement. The score for "provide information about social resources" was low at 18.4%. Of the respondents, 95.8% answered that epilepsy-related knowledge and technical skills were necessary for home healthcare nursing practice, and 87.7% were interested in participating in a workshop on epilepsy.

Conclusion The study revealed an inadequate level of knowledge of epilepsy with dementia and corresponding epileptic seizures, a low awareness of nursing care in collaboration with physicians, and the importance of providing information about social resources. There is a need to offer information and education on the latest knowledge about epilepsy to HHNs.

Key words attitude; epilepsy; home healthcare nurses; knowledge; practice

Epilepsy is a common neurological disorder with a prevalence that ranges from 3.3 to 7.8 of every 1,000 individuals.[1] Epilepsy can develop in all stages of life, from childhood to old age. Recently, cases of epilepsy in older adults have been on the rise.[2] There are cases in which epilepsy resolves; however, many people with epilepsy (PWE) spend the rest of their lives in a community/home setting. In addition to epileptic seizures, PWE face various challenges such as problems with school, employment, independent living and keeping a driver's license. For these reasons, psychological and social supports are necessary in addition to medical treatment.[3] In terms of care for PWE, in addition to medical treatment, psychological and social approaches to care are necessary, as well as comprehensive care on a community basis.[4]

Overseas, in addition to diagnosis and treatment by a physician, PWE are supported by the multidisciplinary cooperation of epilepsy specialist nurses and community care workers.[5–7] The significance of the work of epilepsy specialist nurses has been reported.[8–10] There are also reports of improvements in subject quality of life through the intervention of nurses for PWE.[11]

In Japan, because of problems such as the limited number of hospitals specializing in epilepsy and epilepsy specialists, comprehensive community care systems are not progressing. Those responsible for medical care in community/home settings in Japan are mainly doctors at hospitals/clinics, outpatient nurses, home healthcare nurses (HHNs), residential facility nurses and other similar individuals. To support the super-aging society of Japan, there is an urgent need for the construction of a comprehensive community care system[12]; however, to provide comprehensive support for people living with chronic and/or intractable diseases—including epilepsy—the role of HHNs, which combines the viewpoints of both medical and nursing care, is thought to be critical.[13] Surveys on epilepsy-related knowledge, attitudes

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Abbreviations: HHNs, home healthcare nurses; PWE, people with epilepsy

and practices have been carried out with clinic doctors and group home personnel,[14] yet there have been few studies with HHNs as subjects. Furthermore, the current status of the practices of HHNs for PWE is not clear. Accordingly, this study investigated the epilepsy-related education of HHNs and the current state of comprehensive care for PWE, with the aim of illuminating the epilepsy-related knowledge and attitudes—as well as the current practices—of HHNs.

SUBJECTS AND METHODS

Subjects

Nursing staff at offices affiliated with the Tottori Prefecture Home Healthcare Nursing Station Coordinating Council and at offices affiliated with the Shimane Prefecture Home Healthcare Nursing Station Association were the subjects of this study. The number of surveys distributed was 546.

Survey methods

From June to August 2014, an anonymous, self-administered questionnaire was conducted by mail. The questionnaire and request forms were mailed collectively to a number of staff members at each office. Regarding collection, subjects were asked to send their responses in individual envelopes addressed to the researchers.

Survey contents

In the present study, survey items were selected and a questionnaire was created based on previous research with medical personnel and nursing students as subjects.[15–18] Regarding epilepsy-related knowledge, subjects were asked about the prevalence and cause of epilepsy, symptoms of a seizure, how to respond to a seizure and epilepsy medical treatment and caregiving. For epilepsy-related attitudes, subjects were asked, "For each item, to what degree do you believe PWE are constrained?" for eight items, including those on education, driving, regular employment, travel, friendship, marriage, having a child and social participation, and responses were given on a four-point scale. On the topic of epilepsy-related experience, subjects were asked about their experience thus far with education, meeting PWE and seeing epileptic seizures. Concerning epilepsy-related home healthcare nursing practices, subjects were asked about their home healthcare nursing practices with idiopathic/symptomatic epilepsy, the details of that care, and their intentions regarding home healthcare nursing practices in the future.

Statistical analyses

IBM SPSS 24.0J for Windows (SPSS, Chicago, IL) was used for analyses. Descriptive statistics were calculated for each question item. Additionally, to reveal the relations between experience with home healthcare nursing for PWE and intentions for epilepsy nursing practices, a chi-square test was conducted.

Ethical considerations

The purpose of this study was explained to the chairman of the Tottori Prefecture Home Healthcare Nursing Station Coordinating Council and the chairman of the Shimane Prefecture Home Healthcare Nursing Station Association, and consent to implement the survey was obtained. Next, the survey form was mailed to each station, request forms were attached, and it was explained that survey participation was voluntary; the survey was anonymous, and individual information would not be disclosed; there would be strict handling of collected questionnaires and data entered by subjects; the data would not be used outside of the purposes of the research; and the results would be published at academic conferences or in academic papers. It was also explained in the instructions that, if confirmation of intention to participate was returned with the questionnaire, consent could not be withdrawn after submission as the responses were anonymous. This study was conducted with the approval of the Tottori University School of Medicine Ethical Committee (Approval Number: 2366).

RESULTS

Subject characteristics (Table 1)

Of the 546 distributed questionnaires, 290 (53.1%) were collected, and 285 (52.2%) were valid responses. The average age was 48.9 ± 9.2 years, number of years of nursing practice was 22.6 ± 9.8 years and number of years of home healthcare nursing practice was 7.1 ± 5.5 years. Of the respondents, 185 (64.9%) were employed full-time and 97 (34.0%) were employed part-time. Job position was manager for 55 individuals (19.3%) and staff for 225 (78.9%).

Epilepsy-related knowledge (Table 2)

Of those surveyed, 24.9% answered correctly regarding the prevalence of epilepsy (the correct answer being 1 in 100 individuals). Regarding the cause of epilepsy, the percentages of correct answers in descending order were 86.7% for stroke, 85.3% for head injury and 68.1% for brain tumors. Dementia accounted for 13.3%. Regarding epileptic seizure symptoms, the percentages of correct answers in descending order were 90.9% for "convulsions or shaking," 90.2% for "loss of consciousness," 64.9% for "faint spells" and 61.8% for "drowsiness following a seizure attack."

Table 1. Demographics of the respondents (*n* = 285)

		n	(%)
Mean age, (years) (SD: range)		48.9	(9.2: 24–70)
Mean length of nursing, (years) (SD: range)		22.6	(9.8: 1–50)
Mean length of home healthcare nursing, (years) (SD: range)		7.1	(5.5: 0–20)
Gender	Male	2	(0.7)
	Female	281	(98.6)
	Missing value	2	(0.7)
Prefecture	Tottori	88	(30.9)
	Shimane	193	(67.7)
	Missing value	4	(1.4)
Employment status	Full-time	185	(64.9)
	Part-time	97	(34.0)
	Missing value	3	(1.1)
Position	Manager	55	(19.3)
	Staff	225	(78.9)
	Others	1	(0.4)
	Missing value	4	(1.4)
Education level	Vocational school	251	(88.0)
	Junior college	21	(7.4)
	University	10	(3.5)
	Graduate school	1	(0.4)
	Others	2	(0.7)
Licenses*	Nurse	264	(92.6)
	Public health nurse	6	(2.1)
	Midwife	4	(1.4)
	Assistant nurse	29	(10.2)
	Care manager	53	(18.6)
	Others	5	(1.8)

* Multiple responses

Concerning how to respond to an epileptic seizure, those with high correct response rates were "prevent injury" (90.9%), "prevent choking" (87.7%), "observe seizure symptoms carefully" (84.2%) and "check for consciousness" (79.6%). However, 29.8% gave the incorrect answer of "place something inside the mouth." For epilepsy medical treatment and caregiving, those with high correct response rates were "continue administration of medication as prescribed by the doctor" (98.6%) and "discontinuation of taking medicine may trigger seizures" (89.5%).

Epilepsy-related attitudes (Table 3)

Regarding subjects' thoughts on social restriction due to epilepsy, items with high percentages were "driving" (81.4%), "regular employment" (38.2%) and "having a child" (32.6%). The lower items were "social participation" (10.5%) and "friendship" (6.7%).

Experience and familiarity with epilepsy (Table 4)

Concerning epilepsy education experience, most (92.6%) had learned through lectures when they were nursing students, 21.4% learned by taking a lecture after becoming a nurse and 20.4% had learned through self-study after becoming a nurse. Of those surveyed, 57.5% answered, "I met PWE when I worked at a hospital ward/facility" and 20.7% answered, "I have known PWE in my neighborhood/school/workplace." Of those surveyed, 60.7% had seen an epileptic seizure, and 13.7% had seen an epileptic seizure as an HHN.

Home healthcare nursing experience and practices for PWE

Table 5 shows HHNs' experiences in caring for PWE. Of those surveyed, 6.3% had experience taking care of patients with idiopathic epilepsy in a home healthcare nursing setting, and 41.4% had experience taking care of patients with symptomatic epilepsy in a home healthcare nursing setting. When those with experience taking care of patients with symptomatic epilepsy were asked about the cause of symptomatic epilepsy, the most common response was "stroke."

Regardless of whether it was idiopathic or symptomatic epilepsy, 125 (43.9%) subjects had experience taking care of PWE in a home healthcare setting.

Table 6 shows the nursing practices of HHNs for PWE. When asked about the details of their caregiving, the most common responses (87.2%) were "confirmation of seizure frequency, extent and symptoms" and "assistance with medication." Next were "collaboration with the attending physician" (52.0%), "family care" (49.6%) and "listen to everyday worries" (48.8%). "Provide information about social resources" was low at 18.4%.

Relations between experience taking care of PWE at home and intentions for home healthcare nursing practice for PWE

Of those surveyed, 37.9% responded that they would find it difficult if they became HHNs for PWE in the future, 95.8% answered that epilepsy-related knowledge and technical skills were necessary for home healthcare nursing practice and 87.7% answered that they would like to participate in a lecture or workshop on epilepsy (Table 7).

Table 8 shows the relations between experience

Table 2. HHNs' knowledge of epilepsy (*n* = 285)

		n	(%)
Epilepsy occurs in			
	1 in every 100,000 people (F)	24	(8.4)
	1 in every 10,000 people (F)	62	(21.8)
	1 in every 1,000 people (F)	84	(29.5)
	1 in every 100 people (T)	71	(24.9)
	Don't know	44	(15.4)
What is the cause of epilepsy? (multiple answers permitted)			
	Hereditary disease (T)	122	(42.8)
	Head injury (T)	243	(85.3)
	Stroke (T)	247	(86.7)
	Birth defects (T)	133	(46.7)
	Contagious disease (F)	77	(27.0)
	Mental illnesses (F)	70	(24.6)
	Dementia (T)	38	(13.3)
	Brain tumors (T)	194	(68.1)
What do you think an epileptic seizure is? (multiple answers permitted)			
	Convulsions or shaking (T)	259	(90.9)
	Loss of consciousness (T)	257	(90.2)
	Behavioral arrest (T)	166	(58.2)
	Sudden drop attack with atonia (T)	168	(58.9)
	Rising epigastric sensation (T)	35	(12.3)
	Small convulsions at the ends of the hands and feet (T)	175	(61.4)
	Faint spells (T)	185	(64.9)
	Lip-smacking, chewing or swallowing (T)	82	(28.8)
	Drowsiness following a seizure attack (T)	176	(61.8)
	Headache following a seizure attack (T)	69	(24.2)
What should you do during a seizure? (multiple answers permitted)			
	Prevent choking (T)	250	(87.7)
	Place something inside the mouth (F)	85	(29.8)
	Prevent injury (T)	259	(90.9)
	Call an ambulance immediately (F)	23	(8.1)
	Observe seizure symptoms carefully (T)	240	(84.2)
	Move the patient to a safe area (T)	195	(68.4)
	Check pupillary light reflex (T)	45	(15.8)
	Administer medicine immediately (F)	29	(10.2)
	Shake patient to recover consciousness (F)	7	(2.5)
	Restrain patient to prevent seizure (F)	5	(1.8)
	Check for consciousness (T)	227	(79.6)
	Call a doctor when the duration of seizures is 10 minutes or more (T)	209	(73.3)
Which of the following choices are appropriate for the treatment/care of epilepsy? (multiple answers permitted)			
	Continue administration of medication as prescribed by the doctor (T)	281	(98.6)
	Discontinue taking medicine when seizures stop (F)	1	(0.4)
	Discontinuation of taking medicine may trigger seizures (T)	255	(89.5)
	Understanding that PWE have anxiety about seizures occurring (T)	248	(87.0)
	Understanding that sleep shortage is a trigger of seizures (T)	193	(67.7)
	Understanding surgical treatments for epilepsy (T)	61	(21.4)
	Understanding that PWE have a high risk of depression (T)	87	(30.5)

HHNs, home healthcare nurses; PWE, people with epilepsy. T: correct answer is true. F: correct answer is false.

Table 3. HHNs' responses to questions about their social tolerance toward PWE (*n* = 285)

	Scarce or no limits		Strong or moderate limits		No answer or don't know	
	n	(%)	*n*	(%)	*n*	(%)
Education	243	(85.3)	34	(11.9)	8	(2.8)
Driving	50	(17.5)	232	(81.4)	3	(1.1)
Regular employment	169	(59.3)	109	(38.2)	7	(2.5)
Travel	226	(79.3)	53	(18.6)	6	(2.1)
Friendship	258	(90.5)	19	(6.7)	8	(2.8)
Marriage	231	(81.0)	47	(16.5)	7	(2.5)
Having a child	184	(64.6)	93	(32.6)	8	(2.8)
Social participation	250	(87.7)	30	(10.5)	5	(1.8)

HHNs, home healthcare nurses; PWE, people with epilepsy.

Table 4. HHNs' experience and familiarity with epilepsy (*n* = 285)

	n	(%)
Have you ever studied epilepsy? (multiple answers permitted)		
1) Yes, at school when I was a nursing student.	264	(92.6)
2) Yes, a training program in a hospital when I was a nursing student.	33	(11.6)
3) Yes, by myself when I was a nursing student.	15	(5.3)
4) I took a lecture after becoming a nurse.	61	(21.4)
5) I studied by myself after becoming a nurse.	58	(20.4)
6) I have watched/listened to programs about epilepsy.	48	(16.8)
7) I joined a workshop or an academic society on epilepsy.	16	(5.6)
8) Others	13	(4.6)
Do you know someone with epilepsy? (multiple answers permitted)		
1) I met PWE during student nurse training at hospital.	32	(11.2)
2) I met PWE when I worked at a hospital ward/facility.	164	(57.5)
3) I have a family member/relative with epilepsy.	30	(10.5)
4) I have known PWE in my neighborhood/school/workplace.	59	(20.7)
5) Others	6	(2.1)
Have you ever witnessed a seizure?		
1) I have witnessed a seizure.	173	(60.7)
2) I have witnessed a seizure as an HHN.	39	(13.7)

HHNs, home healthcare nurses; PWE, people with epilepsy.

Table 5. HHNs' experiences in caring for PWE at home (*n* = 285)

	n	(%)
I have taken care of patients with idiopathic epilepsy at home.	18	(6.3)
I have taken care of patients with symptomatic epilepsy at home.	118	(41.4)
I have taken care of patients with idiopathic or symptomatic epilepsy at home	125	(43.9)
What was the cause of your patient's symptomatic epilepsy?		
Stroke	98	(34.4)
Head injury	31	(10.9)
Brain tumors	22	(7.7)
Dementia	6	(2.1)
Others	13	(4.6)

HHNs, home healthcare nurses; PWE, people with epilepsy.

Table 6. Answers to questions regarding nursing practices of HHNs for PWE (*n* = 125)

	n	(%)
What are the nursing functions/responsibilities to be performed by HHNs for PWE at their homes?		
Confirmation of seizure frequency, extent and symptoms	109	(87.2)
Assistance with medication	109	(87.2)
Confirmation of injuries, burns and blows, etc.	45	(36.0)
Confirmation of their understanding of epilepsy and medical treatment	58	(46.4)
Listen to what PWE think about their epilepsy or seizures	44	(35.2)
Listen to everyday worries	61	(48.8)
Guidance in everyday life	54	(43.2)
Provide medical information	33	(26.4)
Provide information about social resources	23	(18.4)
Family care	62	(49.6)
Collaboration with the attending physician	65	(52.0)
I had an embarrassing experience in assessing and treating a seizure of a home healthcare patient.	17	(13.6)
I had an embarrassing experience while collaborating with the attending physician or other co-medical staff members.	12	(9.6)

HHNs, home healthcare nurses; PWE, people with epilepsy.

Table 7. HHNs' views toward taking care of PWE at home (*n* = 285)

	n	(%)
I think it would be difficult to take care of PWE in the future.	108	(37.9)
I agree that epilepsy-related knowledge and technical skills are necessary for home healthcare nursing practice.	273	(95.8)
I would like to participate in a lecture or workshop on epilepsy.	250	(87.7)

HHNs, home healthcare nurses; PWE, people with epilepsy.

Table 8. Relations between experience taking care of PWE at home and intentions for home healthcare nursing practice for PWE

		Do you have experience taking care of PWE in a home healthcare nursing setting?		
		No *n* (%)	Yes *n* (%)	*P* value
Do you think it would be difficult to take care of PWE in the future?	No	59 (48.0)	58 (58.6)	0.115
	Yes	64 (52.0)	41 (41.4)	
	Total	123 (100)	99 (100)	
Do you agree that epilepsy-related knowledge and technical skills are necessary for home healthcare nursing practice?	Strongly	49 (33.6)	44 (35.2)	0.798
	Moderately	93 (63.7)	79 (63.2)	
	Scarcely	4 (2.7)	2 (1.6)	
	No at all	0 (0.0)	0 (0.0)	
	Total	146 (100)	125 (100)	
Would you like to participate in a lecture or workshop on epilepsy?	Strongly	18 (12.7)	22 (17.6)	0.022*
	Moderately	105 (73.9)	99 (79.2)	
	Scarcely	17 (12.0)	3 (2.4)	
	No at all	2 (1.4)	1 (0.8)	
	Total	142 (100)	125 (100)	

PWE, people with epilepsy. Statistical evaluation is performed by χ^2 test. *$P < 0.05$.

taking care of PWE at home and intentions for home healthcare nursing practice for PWE. Regarding the items, "I think it would be difficult to take care of PWE in the future" and "Epilepsy-related knowledge and technical skills are necessary for home healthcare nursing practice," there were no relations with home healthcare nursing experience for PWE. However, for the item, "I would like to participate in a lecture or workshop on epilepsy," a significant difference was observed between home healthcare nursing experience for PWE. The per-

centage of those who responded, "I would really like to participate," was higher for the group with experience in home healthcare nursing for PWE than for the group with no experience.

DISCUSSION

When compared to previous literature,[15–19] the epilepsy-related knowledge of the studied HHNs was found to be higher. In particular, the rate was 41.4% for those with experience in home healthcare nursing for patients with symptomatic epilepsy. As for the cause of epilepsy, the high correct answer rate was surmised to result because of their experience with stroke, head injury, brain tumors and such. On the other hand, the correct answer rate for "dementia" as a cause of epilepsy was low. Dementia—particularly Alzheimer's disease—is known to be one risk factor for epilepsy, and it has been reported that the lifetime prevalence of epilepsy in patients with Alzheimer's disease is between 1.5% and 64%.[20] In Japan, it is predicted that there will be an increase in the number of individuals with dementia in the future due to the aging population, and there is a high possibility that the number of PWE will increase. Consequently, it is thought to be necessary to provide HHNs with information regarding epileptic seizures accompanying dementia and how to respond.

On the subject of responding to epileptic seizures, the overall correct response rate was high; however, there were also incorrect replies such as "place something inside the mouth" (29.8%), and vague responses such as "call a doctor when the duration of seizures is 10 minutes or more" (73.3%). As this is important knowledge for offering support to PWE in the community, it is considered necessary to provide information about appropriate responses and to improve methods of collaboration with doctors.

For epilepsy-related attitudes, many individuals responded that there were constraints on "driving." In many countries, driving for PWE is restricted or prohibited.[21] In the current system in Japan, to determine if it is appropriate for an PWE to drive, a medical certificate from a continuously examining physician specifying that no seizures have occurred within the past two years and one specifying that there have been no simple partial seizures involving impairment of consciousness or movement in the past year are necessary.[22, 23] There is a need for HHNs to be familiar with all systems relating to daily life, and, as the driving restrictions are similar to those for elderly individuals and those with dementia, they are considered to be of particular interest.

More than 80% responded that there were no restrictions regarding "education," "friendship," "marriage" and "social participation"; however, regarding "regular employment," approximately 40% responded that there were restrictions. For the home healthcare nursing practice of subjects supporting all aspects of daily life, support for employment was thought to be a challenge for the future.

Regarding home healthcare nursing practices, whether with idiopathic or symptomatic epilepsy, over 40% of those surveyed had experience taking care of PWE in a home healthcare setting. Regarding the details of the HHNs' care provided to PWE, a high percentage was related to medical treatment, such as "confirmation of seizure frequency, extent and symptoms" and "assistance with medication." In addition to this, HHNs provide care in their everyday life, such as "listening to everyday worries," "confirmation of their understanding of epilepsy and medical treatment," "guidance in everyday life." Furthermore, "collaborating with the attending physician" and "family care" were considered necessary in home healthcare settings. On the other hand, the percentage was low for "providing information about social resources." Development of resources and provision of information on social resources that PWE can utilize is necessary.

It was revealed that many nurses would find it difficult if they became HHNs for PWE. Additionally, the more experience one had with epilepsy home healthcare nursing, the higher the desire to attend epilepsy training became. However, no significant difference was observed for feelings about the necessity of epilepsy knowledge/technical skills. Accordingly, the need for nursing care and the current status of daily life for PWE should be common knowledge for HHNs. Moreover, as was revealed in this study, knowledge about epilepsy accompanying dementia, response to epileptic seizures and collaboration with doctors and training including information on social resources are considered necessary hereafter for HHNs.

This study has some limitations. First, the subjects were HHNs of the San-in region, which implies that our findings may not be generalizable to the situations of HHNs of other areas. A further limitation is that the use of a close-ended questionnaire does not reveal further details about the reasons for inadequate knowledge and practices. Thus, there is a need for further study to reveal problems in the practices of HHNs for PWE.

In conclusion, as a measure to deal with the super-aging society, the construction of a comprehensive community care system is becoming an urgent issue in Japan. Not only for elderly individuals, but for all individuals with disabilities, regardless of age, there is a need to create communities that are comfortable to live

in. HHNs, who understand the viewpoints of both medical treatment and human services, should have a deep knowledge of epilepsy, support the lifestyle of PWE and coordinate services thought to be necessary for the progress of comprehensive care for PWE.

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