

Older people and knowledge of epilepsy: GPs can help

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Background and objective

Epilepsy is a common neurological disease with a high prevalence in people aged 65 years or older. Therefore, an understanding of the disease is important. The objective of this article was to determine older people's knowledge of epilepsy.

Methods

Electronic or paper-based surveys were completed by people aged 65 years and older.

Results

Five hundred and seventy-two surveys were completed, including 100 from people with epilepsy. Those with epilepsy had relatively poor knowledge of their condition, but they answered some questions significantly more correctly than participants without epilepsy. The main predictor of knowledge was clear information from a health professional. Two-thirds of those with epilepsy had their condition managed by a general practitioner.

Discussion

Older people with epilepsy need more information on their condition to facilitate better care management.

Epilepsy is a common neurological disease that is defined by the international peak body, the International League Against Epilepsy (ILAE), as 'at least two or more unprovoked (or reflex) seizures occurring more than 24 hours apart, or one unprovoked (or reflex) seizure with the probability of further seizures, that is similar to the risk associated after two unprovoked seizures occurring over the following 10 years, or a diagnosis of an epilepsy syndrome'.¹ Up to 10% of Australians will have a seizure at some time in their lives; internationally, up to 1% of the population has a diagnosis of epilepsy,² with about 224,000 Australians having this disease. Epilepsy is associated with increased mortality and morbidity risk, including higher rates of conditions such as anxiety and depression.³ Despite large milestones in understanding how epilepsy affects people's lives, knowledge of epilepsy is poor.⁴

Epilepsy is more common in people aged 65 years or older⁵ because of the ageing of the population and increase of diseases such as stroke and dementia.^{6,7} Yet, there is a lack of studies about older people with epilepsy.⁸ While control of seizures was reported to be better in older people than in other age groups,⁹ older people experience greater comorbidities, often taking multiple medications, which makes management challenging.¹⁰ Many general practitioners (GPs) are unaware of the higher prevalence of epilepsy among older people.¹¹ Accurate diagnosis may be delayed and effective

management not provided. People who have epilepsy diagnosed late in life have a lower quality of life¹² and more psychosocial problems than people without epilepsy.¹³ They benefit from education about their epilepsy for improved management and a better longer term prognosis.

Epilepsy care management provided through GPs is arguably the missing link in a comprehensive, interdisciplinary patient-centred approach.¹⁴ Although GPs may treat only small numbers of patients with epilepsy (between five and 10), they are important in providing positive outcomes for patients¹⁵ between consultations with their neurologists or epileptologists. Hence, collaboration and communication between GPs and specialists are essential. While evidence from the UK has shown that GPs followed up 91% of patients⁹ and are less likely than some other healthcare providers to refer to specialist epilepsy clinics,¹⁶ GPs need to be encouraged to refer patients on to specialists.

There is great scope for increased knowledge and understanding of epilepsy in older people. A two-day educational program for people with epilepsy was found to significantly increase knowledge, which led to better experiences of epilepsy (including more positive psychosocial states).¹⁷

With clear information about epilepsy treatment and consequences, patients may cope better and manage their condition.¹⁸ Information from GPs, encompassing good-quality annual reviews, medication advice and other targeted information,

improves patients' experiences and care management.¹⁹

The aim of this study was to evaluate knowledge of epilepsy in people aged 65 years and older, with or without epilepsy, and identify the factors influencing their knowledge, to understand how knowledge of epilepsy is gained.

Method

Ethics approval was obtained from Deakin University's Human Research and Ethics Committee (reference no. 2014–158). Data were collected from July to October 2015.

People aged 65 years and over were recruited Australia-wide to complete an online survey (or if requested, a paper survey). The inclusion criterion was people aged 65 years and older. Informed consent was implied from completion of the survey. Participants were recruited by articles and advertisements (with links to the survey and phone numbers of researchers) in the magazine COTA CONNECT, and on the Epilepsy Foundation and National Ageing Research Institute websites. In addition, people on the Epilepsy Foundation's Australian Epilepsy Research Register²⁰ and Clinical Services Register were emailed information about the study, including a link to the online survey.

The survey consisted of two parts. The first, completed by all participants, consisted of sociodemographic information and knowledge of epilepsy. Knowledge was determined using a scale that was derived from the validated epilepsy knowledge questionnaire (EKQ) based on correct responses identified as 'True' or 'False'.²¹ The original EKQ contains 55 items, which covers medical and social aspects. A number of other studies have used different versions of the EKQ.^{22–24} The version for this study included 20 items that were derived from disability questions from the EKQ, and contained three additional items specifically targeting knowledge about older people with epilepsy. These three items were:

- People over 65 are more likely to get epilepsy than younger people.
- Antiepileptic medication levels can fluctuate significantly in older people.

- People with stroke or dementia are more likely to get epilepsy than people without these conditions.

The second part, which was completed only by participants with epilepsy, included items about the disease and its management:

- number and type of seizures
- medications
- comorbidities
- whether they had an epilepsy management plan
- effects of epilepsy on their lives.

Data analysis

Correlations (Cramer's V) were used for the EKQ to determine significant differences between those with and without epilepsy. Differences between those with and without epilepsy on the 20-item and 23-item knowledge scales were determined using unpaired t-tests. Block recursive regression was used to determine the main factors to predict participants' knowledge of epilepsy. This is similar to a hierarchical linear regression where total effects (direct and indirect effect combined) are measured.

Results

A total of 572 surveys were completed, including 463 participants without epilepsy and 100 with epilepsy (Table 1). Nine participants did not answer the question about epilepsy status. Most of the participants were female and aged 65–74 years; 68% of those with epilepsy and 71% of those without epilepsy were female. The highest proportion of those with epilepsy was in the 65–74 years age group and lowest in the 85 years and older age group (Table 1). Of the whole sample, more than one-third lived in their own home/apartment/unit with family or others, while 15.0% of those with epilepsy lived in residential high care, compared with 8.8% of those without epilepsy. Seventy-eight per cent were diagnosed with epilepsy before 65 years of age, while 22% were diagnosed aged 65 years and older.

Part 1: All respondents – Knowledge of epilepsy

Table 2 shows details of respondents

providing the correct responses to each of the 23 statements as an indicator of their knowledge. The correct answers to the statement (true or false) are indicated by 'T' or 'F' in brackets, showing significant differences between participants with and without epilepsy.

Knowledge scales

On the knowledge scale comprising 20 items, participants with epilepsy answered an average of 15 questions correctly (range: 9–20). This was not significantly more than for participants without epilepsy (14.4 items correct; range: 7–19). On the 23-item knowledge scale, participants with epilepsy answered an average of 15.8 questions correctly (range: 10–22); participants without epilepsy answered 15.4 items correctly (range: 8–22). As with the 20-item scale, the difference in scores between the two groups was not significantly different.

Knowledge items

In four items in Table 2 (numbers 6, 9, 11 and 13), there was a significant difference in the number of correct responses achieved with a higher correct rate by participants with epilepsy than those without epilepsy. For item number 22, there were significantly more correct responses by participants without epilepsy than those with epilepsy.

Least knowledge items

Four items with the least number of correct responses were shared for all respondents. These included:

- People over 65 are more likely to get epilepsy than younger people (T) – participants with epilepsy: 14.3% correct; participants without epilepsy: 15.1% correct.
- On a job application, a patient should always disclose his/her epilepsy condition (F) – participants with epilepsy: 24.2% correct; participants without epilepsy: 18.1% correct.
- People with stroke or dementia are more likely to get epilepsy than people without these conditions (T) – participants

with epilepsy: 27% correct; participants without epilepsy: 22.1% correct.

- All people with seizures should avoid working with open machinery (F) – participants with epilepsy: 29.9% correct; participants without epilepsy: 20.1% correct.

Part 2: People with epilepsy-specific questions

One hundred participants with epilepsy aged 65 years and older completed the second part of the questionnaire. Sixty-six participants with epilepsy reported using a GP to manage their condition. Of these, 14 also used an epilepsy specialist and 36 also

used a neurologist. Nineteen participants used a GP without a specialist.

Predictors of knowledge

Thirty-six participants (54.5%) who used a GP were very satisfied with the clarity of information; 16 (24.2%) were somewhat satisfied; 12 (18.2%) were neither satisfied nor dissatisfied; and two (3.0%) were somewhat dissatisfied. The main predictor of knowledge for participants with epilepsy was satisfaction with the clarity of the information given by a medical professional. It had a significant effect on the 20-item and 23-item knowledge scales. On the 23-item scale, a block recursive regression was

undertaken. Satisfaction with the clarity of information (beta: -0.237 ; b [unstandardised coefficient]: -0.028 ; P : 0.048) had a significant effect and is stronger than gender, age, whether living in the city/country, number of seizures, number of epilepsy medicines and whether having a friend/family member with epilepsy. The model had a modest R-square (13% of variability explained).

Discussion

Knowledge about epilepsy has been reported as poor in other studies. A study in Poland of people with epilepsy showed that 75% had very little understanding of the course of the disease or its aetiology.⁴ Older people with epilepsy in the reported study knew slightly more about epilepsy than older people without the condition (15.8 of 15.4). Goldstein et al²³ found that only 25% of respondents felt they had received sufficient information regarding the side effects of anti-epileptic medications, indicating limited access to knowledge. These studies confirm that people with epilepsy in the community may have relatively poor knowledge and understanding of epilepsy. This can have an impact on activities such as self-managing the condition, and comprehending and interpreting advice from medical professionals.

Two of the least correct responses provided by participants with epilepsy in this study were about epilepsy in older people. This poorer knowledge could be addressed by GPs providing patients with an increased understanding of the condition and its management. This would lead to more positive experiences for patients and support best practice in care management, enhancing quality of life. That little is known by older people with epilepsy about the onset and comorbidities of epilepsy at an older age is a cause of concern and may lead to them, their family and carers dealing less effectively with their condition.

For GPs, this study has shown that patients may have poor knowledge of particular aspects of the condition. For example, this study found that 54.3% of participants with epilepsy answered the

Table 1. Demographics of survey respondents (n = 572)

	Total respondents (n = 572) (%)	People with epilepsy (n = 100) (%)	People without epilepsy (n = 463) (%)
Gender			
Female	406 (71.0)	68 (68.0)	331 (71.5)
Male	166 (29.0)	32 (32.0)	132 (28.5)
Age groups			
65–74 years of age	286 (50.0)	61 (61.0)	220 (46.5)
75–84 years of age	191 (33.4)	30 (30.0)	158 (34.1)
≥85 years of age	95 (16.6)	9 (9.0)	85 (18.4)
Age			
Range	65–96 years of age	65–94 years of age	65–96 years of age
Mean	75.6 years of age	73.4 years of age	76.1 years of age
Standard deviation	7.9 years of age	7.3 years of age	8.0 years of age
Living arrangements			
Own home/apartment/unit – Living alone	170 (29.8)	29 (29.0)	139 (30.0)
Own home/apartment/unit – Living with family or others	201 (35.2)	34 (34.0)	162 (35.0)
Residential care – High care	50 (8.8)	15 (15.0)	34 (7.3)
Residential care – Low care	30 (5.3)	5 (5.0)	25 (5.4)
Hostel	8 (1.4)	2 (2.0)	6 (1.3)
Retirement village	95 (16.6)	13 (13.0)	82 (17.7)
Caravan park	2 (0.4)	–	2 (0.4)
No fixed abode	1 (0.2)	–	1 (0.2)
Other (eg in carer's home)	14 (2.5%)	–	12 (2.6%)

Table 2. Number (and percentage) of respondents giving correct responses to knowledge statements about epilepsy

Item number	Statement	Total respondents (missing in brackets)	Older people with epilepsy	Older people without epilepsy	Cramér's V p
1	Epilepsy is a contagious disease (F)	561 (11; 1.9%)	98 (100%)	441 (96.7%)	
2	People with epilepsy cannot drink alcoholic beverages (F)	537 (35; 6.1%)	73 (75.3%)	317 (73.2%)	
3	People with epilepsy should avoid strenuous work because this can provoke seizures (F)	537 (35; 6.1%)	80 (83.3%)	337 (77.6%)	
4	An electroencephalogram (EEG) can always prove the diagnosis of epilepsy (F)	507 (65; 11.4%)	50 (54.3%)	219 (53.5%)	
5	People with epilepsy are as capable as other people (T)	542 (30; 5.2%)	92 (93.6%)	378 (86.3%)	
6	All people with seizures should avoid working with open machinery (F)	542 (30; 5.2%)	29 (29.9%)	88 (20.1%)	0.100 p 0.02
7	Every seizure destroys a number of nerve cells in the brain (F)	512 (60; 10.4%)	59 (63.4%)	219 (53.0%)	
8	People with seizures should not swim without an accompanying person (T)	544 (28; 4.9%)	76 (78.4%)	357 (81.0%)	
9	All people with epilepsy should avoid flashing or strobing lights (F)	528 (44; 7.7%)	50 (51.5%)	141 (33.3%)	0.121 p 0.008
10	In most cases, doctors can control epileptic seizures with medication (T)	553 (19; 3.3%)	93 (93.0%)	415 (92.8%)	
11	If your seizures are controlled for some months, you can reduce the dose of anti-epileptic medication (F)	526 (46; 8.0%)	73 (76.8%)	282 (66.4%)	0.103 p 0.009
12	All people with epilepsy have similar symptoms (F)	538 (34; 5.9%)	87 (89.7%)	453 (85.3%)	
13	If a patient expects a seizure, he/she should take an additional dose of anti-epileptic medication (F)	502(70; 12.2%)	86 (89.6%)	287 (71.9%)	0.158 p 0.000
14	On a job application, a patient should always disclose his/her epilepsy condition (F)	547 (25; 4.4%)	24 (24.2%)	83 (18.8%)	
15	People with epilepsy can take an active part in sports (T)	547 (25; 4.4%)	96 (98.0%)	414 (93.5%)	
16	An epileptic seizure always results in loss of consciousness (F)	525 (47; 8.2%)	76 (78.4%)	330 (78.4%)	
17	People whose seizures only occur during sleep may hold a driver's license (T)	510 (62; 10.8%)	29 (31.5%)	159 (38.7%)	
18	Everyone can have a seizure, given the appropriate circumstances (T)	528 (44; 7.7%)	59 (64.1%)	291 (67.8%)	
19	Blood samples can be used to measure the concentration of anti-epileptic medication in the body (T)	503 (69; 12.1%)	83 (88.3%)	370 (91.4%)	
20	Epilepsy is a symptom of mental illness (F)	546 (26; 4.5%)	91 (93.8%)	409 (92.5%)	
21	People >65 years of age are more likely to get epilepsy than younger people (T)	536 (36; 6.3%)	14 (14.3%)	65 (15.1%)	
22	Antiepileptic medication levels can fluctuate significantly in older people (T)	477 (95; 16.6%)	44 (50.6%)	264 (68.6%)	0.141 p 0.002
23	People with stroke or dementia are more likely to get epilepsy than people without these conditions (T)	512 (60; 10.5%)	24 (27.0%)	92 (22.1%)	

F, correct response is false; T, correct response is true

item 'An electroencephalogram (EEG) can always prove the diagnosis of epilepsy' correctly. Interestingly, this was considerably lower than a study by Dougherty et al²² in which 92% of correct responses were achieved for a similar item 'an EEG can be used to diagnose epilepsy'. Another item in the Dougherty et al study, 'If you forget to take [anti-epileptic drugs] for a day, it is usually OK to take two doses together', resulted in only 18% correct responses. Many of the items in the knowledge scale refer to activities that may limit people with epilepsy or may be accommodated into their lifestyle, such as driving, swimming, playing sport and using machinery. As such, knowing what is safe to engage in and what is prohibited may increase the security and safety of older people with epilepsy.

The current study found that the main predictor of better knowledge for people with epilepsy was clear information provided by their medical professional. A UK study reported that about two-thirds of people with epilepsy used a GP to manage their condition,⁸ which is similar to that found in the current study. GPs have an important role in the management of epilepsy and in improving older people's knowledge about epilepsy,¹⁵ offering ongoing risk assessment, education, comorbidity management and monitoring.²⁴

Strengths and limitations

A larger sample of participants with epilepsy would have enhanced the study results. However, as it is a community sample, it reflects issues for older people with epilepsy across a wide spectrum.

Conclusion

Older people with epilepsy had slightly better knowledge of epilepsy than those without the condition. Those who had the best knowledge and understanding of the condition had received clearer information from their healthcare professional.

Implications for general practice

- A main predictor of an increased knowledge in older people with epilepsy,

and hence an understanding of their condition, was clearer information from their GP.

- GPs are pivotal in improving the understanding of epilepsy and its management among older patients.

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