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**A call for better information about epilepsy: the patients' perspective – an
online survey**

Running title: Epilepsy patients want better information

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Highlights

- More than 90% of patients with epilepsy wanted general information about epilepsy
- Over 75% wanted information on more specific issues, like epilepsy surgery
- 6.6% to 91.9% reported having received the information they wanted
- Male gender was an factor for receiving information about epilepsy surgery

Abstract

Purpose: For people with epilepsy (PWE), insufficient information and knowledge about the disease might have a negative influence on outcome and lead to poorer quality of life. In contrast, good information may increase empowerment and reduce stigma. This study investigated whether Norwegian PWE want information about different epilepsy-related issues, whether they actually obtain the information that they seek, and the extent to which they are satisfied with the information they receive. Furthermore, we examined which factors that might have influenced the degree of specific information given to PWE.

Methods: We invited PWE visiting the homepage of the Norwegian Epilepsy Association to complete a web-based questionnaire about their perspective on obtaining information about epilepsy-related issues. The survey was accessible for a four-month period during 2017.

Results: More than 90% of respondents (n=1182) wished general information about epilepsy, and over 75% wanted information on more specific issues, like epilepsy surgery. Depending on the subject, the proportion of respondents that reported receiving the information they wished varied from 6.6% to 91.9%. Obtaining information about epilepsy surgery and neurostimulation was significantly associated with male gender. Having tonic-clonic seizures was associated with obtaining information about the diagnosis, an organized lifestyle, regular sleep, and consumption of alcohol.

Conclusions: This study provides insights on how PWE experience provision of relevant information about epilepsy. Although most PWE considered that they obtained information on general epilepsy issues, most PWE interested in information on non-medical treatments and psychosocial issues reported that they did not obtain the information they wanted.

Keywords Epilepsy, Patient information, Patient knowledge, Questionnaire, Patient perspective

Introduction

Epilepsy is one of the most common neurological disorders affecting more than 70 million people worldwide and is characterized by recurrent unpredictable epileptic seizures [1]. In Western countries, the prevalence of epilepsy is about 0.6% [2].

Kale described the history of epilepsy as “4000 years of ignorance, superstition and stigma, followed by 100 years of knowledge, superstition and stigma” [3]. If people with epilepsy

(PWE) do not have access to sufficient information and knowledge about the disease, this might have a negative influence on disease outcome and result in a poorer quality of life [4]; in contrast, good access to relevant and clear information may increase empowerment and reduce stigma [5].

Most studies that evaluate the level of epilepsy knowledge among PWE conclude that there are unmet needs for provision of better information and counselling in this patient group [6-14]. Nevertheless, a large study with over 6000 participants, concluded that European PWE are reasonably well informed about the disease, based on information retrieved by questionnaire via epilepsy support groups in 10 European countries [15].

Most studies assessing the objective knowledge of PWE about epilepsy use a questionnaire approach [7, 9, 10, 14, 15]. Relatively few studies have investigated the patients' perspective and evaluated whether the patients actually receive the information that they would like from healthcare providers, and whether they are satisfied with the information that they have received [5, 6, 11, 12].

In our opinion, thorough knowledge about the disease may help patients to reduce fear associated with seizures, improve adherence to treatment, increase their ability to cope with daily life challenges, reduce stigma, recognize side effects, avoid seizure-precipitating factors and thereby achieve better seizure control.

The aim of this study was to investigate the extent to which Norwegian PWE would like information about various epilepsy-related issues, whether they actually obtain such information, and the extent to which they are satisfied with the information that they receive. Furthermore, we examined whether factors like gender, age, being seizure free or having tonic-clonic seizures influenced the degree of specific information given.

Methods

Study population

This study was a collaboration between the National Center for Epilepsy and the Norwegian Epilepsy Association (NEA). An online questionnaire (supplementary material) was developed and made available on Association's homepage, as a pop-up for all those who visited the page between April 1st 2017 and September 5th 2017. Each participant could complete the questionnaire only once.

PWE visiting the homepage were asked to complete the questionnaire regarding information about epilepsy-related issues. Questions were selected following a thorough discussion among colleagues at the National centre for epilepsy and advisors at NEA. Questions included background information and also covered the patient's epilepsy, current treatment, and follow-up. In order to determine whether the respondents wished information about epilepsy-related issues, whether they had been provided with such information, and how they perceived the quality of this information, the participants were requested to answer the following questions: "Have you been informed by your healthcare provider on: "The diagnosis", "Drug treatment", "Epilepsy surgery", "Dietary treatment", Vagus nerve stimulation", "Other neurostimulators", "Treatment with cannabis" and "Adverse effects"". The respondents could choose between the following alternative answers for each of these questions: "No information", "Some information, but want more", "Yes, good information", "I do not remember" or "Do not want information/not relevant".

The questionnaire also included the following questions: "Has your physician or epilepsy nurse provided you with information on the following issues: "Routine use of anti-epileptic

drug intake”, “Organized lifestyle”, “Regular sleep”, “Contraception and pregnancy”, “Concentration and memory problems”, “Depression”, “Anxiety”, “Sexual problems”, “Diet and weight”, “Regulations regarding driving” and “Alcohol consumption”. The respondents could choose between the same alternative answers as listed for the previous set of questions.

During analysis, we dichotomized the answers into different groups.

In order to investigate the proportion of respondents who wished to be informed about particular issues, we dichotomized the responses into: “Do not want/not relevant” versus “no information”, “some information, want more”, “yes, good information”, and “I do not remember”.

In order to determine whether the respondents had obtained any information on the specific issues listed, we dichotomized the responses into: “no information” versus “some information, want more” and “yes, good information”.

The quality of information obtained was assessed by comparison of: “some information, want more” with “yes, good information”.

The study was approved by the Regional Ethics Committee (ref.no.:2017/563) prior to implementation.

Statistical methods

IBM SPSS Statistics version 25, release 25.0.0.1. (SPSS Inc, Chicago, IL, USA) was used for statistical analyses. All p-values reported here are based on two-sided tests, with a

significance level of 0.05. To test possible group differences, Pearson's chi-square tests were performed. We further applied Hosmer's step-down procedure that permits variables significant at the 0.25 level to be included in the multivariate logistic regression model [16]. Odds ratios and confidence intervals (CI) at a level of 95% were calculated. Variables tested were gender, above or below the mean age (41.8 years) of the participants, having tonic-clonic seizures, and having been seizure free for the previous 12 months.

Results

During the study period, 48,249 users visited the website, and 1,182 people with epilepsy participated in the survey by completing the questionnaire, at least partly. In addition, 677 answered as carers or family members on behalf of the individual with epilepsy. Additionally, 231 responders answered a different questionnaire in the capacity of being a carer. Two hundred seventy eight were health care providers. Only answers from PWE were included in the analyses. Demographic and clinical characteristics of the participants are summarized in Table 1.

More than 90% of the respondents reported that they wished general information about epilepsy (Diagnosis, AEDs and routine use of AEDs, Adverse events, organized lifestyle, regular sleep, driving regulations, consumption of alcohol). Also information on cognitive and psychiatric issues (concentration and memory, depression and anxiety) was requested by more than 90%. The proportion of respondents wanting information about specific issues (epilepsy surgery, vagus nerve stimulation, other neurostimulators, treatment with cannabis, dietary treatment, sexual problems) was somewhat lower; 75-79%. (Figures 1a and 1b).

The percentage of respondents who reported that they had received information varied extensively depending on topic, with only 6.6% reporting that they had received information about cannabis use as opposed to 91.9% reporting that they had received information about the diagnosis. The difference between the proportion wishing information and the proportion receiving information was small (<20%), and more than 70% of the respondents were satisfied with the received information for routine use of AED treatment, an organized lifestyle, driving regulations and regular sleep. Satisfaction with the received information was between 70% and 50% for issues like diagnosis, AED treatment, contraception and pregnancy, and consumption of alcohol. The corresponding difference between proportions wishing and receiving information was moderate (20%-40%) for information regarding adverse events, which was rated as satisfactory by less than 50% of respondents. A considerable difference (>40%) between the proportion wishing information and the proportion receiving information was found for vagus nerve stimulation (satisfaction with information 70%), epilepsy surgery and dietary treatment (satisfaction with information 50% -70%) and use of other neurostimulators, treatment with cannabis, and information about cognitive problems, depression /anxiety, nutrition and sexual problems (satisfaction with information below 50%) (Figure 1a, 1b and 2). Among the female respondents, 78.6% wanted information about contraception and pregnancy and, of these, 65.2% reported having received information on this topic.

When the issues of diagnosis, AED use, epilepsy surgery, adverse events, controlled use of antiepileptic drugs, organized lifestyle, regular sleep, concentration and memory, depression and anxiety, sexual problems, driving regulations and consumption of alcohol were pooled together, overall information provision was calculated to be 71.3% (all answers reporting that information was provided divided by the number of all responses).

Male gender was found to be an independent variable associated with having obtained information about epilepsy surgery, vagus nerve stimulation, other neurostimulation and nutrition and weight, while female gender was associated with having obtained information about contraception and pregnancy. Being older than the mean age was associated with having obtained information about epilepsy surgery, and being younger was associated with having been informed about adverse events and contraception and pregnancy. Being seizure free was associated with having obtained information about issues around driving regulations and consumption of alcohol, whereas not being seizure free was associated with having obtained information about non-pharmacological treatments (epilepsy surgery, dietary treatment, vagus nerve stimulation, and other neurostimulation). Having tonic-clonic seizures was associated with having been informed about the diagnosis, organized lifestyle, regular sleep, and consumption of alcohol (Table 2).

Discussion

In this study, a nationwide online survey investigated whether PWE in Norway considered themselves to be well informed about different epilepsy-related issues. The size of our sample of 1.182 exceeds that of most other similar studies [5, 6, 12].

Overall, this study shows that although the wish for information about various aspects of epilepsy among PWE in Norway is generally high, it is only partially met by healthcare providers.

To our knowledge, few studies have investigated the patients' wish for information. Prinjha et al. explored the need for information among PWE in a qualitative study (n=35), and found

that many people wished more information about treatment options, and the advantages and disadvantages of the different AEDs [12].

In our study, more than 90% of PWE reported that they wanted general information about the disease. However, many of the respondents also wanted information on epilepsy-related topics not necessarily of particular relevance for most PWE, such as non-medical treatments (epilepsy surgery, neurostimulator treatment, or dietary treatment), and treatment with cannabis. About 40% of the respondents had been seizure free for at least 12 months. Still, at least 70% requested information on each topic.

Few studies have been published that explore the patients' perspective regarding provision of information to PWE. In 2000, Poole et al. [11] conducted a survey among PWE in the UK, either in primary (n=1652) or specialist care (n=742) to determine whether they had received information on various epilepsy-related issues. No information on seizure freedom in the two groups of respondents is provided. In the primary care group, 51.7% had received information and in the specialized care group 59.4% had received information. In particular, 70-80% of respondents had obtained information on topics like driving restrictions, free drug prescriptions, adverse effects of AEDs, consumption of alcohol, and photosensitivity [11]. In 2015, Bennett et al. conducted a similar study based on PWE attending an epilepsy specialist center (n=102). In this group, 67.6% overall had received information on epilepsy-related issues, with more than 80% having obtained information on driving restrictions, alcohol consumption, and adequate sleep [6].

Although the proportion of PWE who, overall, received information in our study was 71.3%, it is important to take into account the topics being considered. The topics included in the overall information in our study differed from those used by Poole et al. [11] and Bennett et

al. [6]. The difference in proportions of PWE who wanted and obtained information on specific topics was greatest regarding psychosocial and cognitive issues, as well as non-pharmacological treatments. Although these issues overlap with adverse events, our results nevertheless indicate that discussion of these issues is an unmet need of those participating in our study.

The majority of studies regarding knowledge among PWE, evaluates how much PWE know about the condition, [7, 9, 10, 14, 15], rather than whether or not information is made available. Doughty et al. [15] found that lack of knowledge was significantly associated with a higher mean age, lower levels of educational achievement, prolonged duration of epilepsy, occurrence of “major” seizures, and high seizure frequency. Mameniskiene et al. [10] used a modified epilepsy-knowledge questionnaire and, similarly, found obtaining lower scores was significantly associated with age over 30 years, lower levels of educational achievement, living in rural areas, and longer epilepsy duration. None of the studies found any association with gender. In contrast, we found that, apart from interest in non-medical treatment, there was also a significant association between male gender and having received information about nutrition and weight. As it has been shown that more men than women in Norway are overweight [17] some physicians may be of the opinion that male patients may be less aware of weight and dietary issues. With respect to age, we found an association between younger age and having obtained information about contraception and pregnancy, adverse events, and regular sleep. This may support the findings from other studies, where greater knowledge about epilepsy was apparent in younger patients. Possibly, younger persons are more inclined to ask for information and/or health care providers might prioritize informing younger patients. Experiencing tonic-clonic seizures might underline the severity of the

disease, and thereby the need for information, and was associated with patients who had obtained information about some of the more general issues in our study.

Epilepsy surgery as a possible treatment option for PWE with refractory epilepsy has long been reported to be underutilized [18]. Studies which have assessed neurologists' knowledge of, and attitude towards, epilepsy surgery have generally indicated a rather cautious attitude and a barrier towards referral of patients to epilepsy surgery [19-20]. This outlook is also likely to influence the extent to which information is provided on the issue. That information about epilepsy surgery was associated with lack of freedom from seizures may be considered unsurprising, however it is less obvious why obtaining information about epilepsy surgery and neurostimulation treatment (including vagus nerve stimulation) was also significantly associated with being male.

The provision of information and the quality of information provided regarding cannabis treatment scored was particularly inadequate. This may reflect that this treatment is currently not registered as a part of the regular epilepsy treatment in Norway.

The average duration of epilepsy among participants in our study was 20 years. With such a long duration of the disease one would assume that they were well informed. But there is also a risk that health care providers assume that information has been given at an earlier stage and focus more on informing patients with newly diagnosed epilepsy.

We are aware that various limitations are associated with this study. Only about 2.5 % of the persons visiting the homepage participated in the survey. Almost 50.000 visitors constitute about 1% of Norway's population. An explanation may be that during the study period, when searching for epilepsy on the Norwegian Google site, the homepage of the Epilepsy Association was the first to pop up. That means that everybody in Norway looking for

information about epilepsy, not just patients and family members, may have visited the homepage of the NEA in the study period. This may imply that the majority of those visiting the homepage did not have epilepsy. However, as we do not have any information about visitors who chose not to participate, we cannot exclude a selection bias. The proportion of seizure-free patients (40.7%) was lower than expected in a representative sample of the general Norwegian epilepsy population. This may indicate a bias towards patients with more severe epilepsy being included in the study. Further limitations are the known problems with the validity of questionnaires based on close-ended questions, and a potential selection bias towards those with a greater need for information than the “average” PWE. Furthermore, we have no verification that the respondent actually had or had not received information from health personnel. Similarly, we have no verification regarding the quality of the information that respondents had received from healthcare providers. With regard to age we choose rather to use over/under mean age as a variable than differentiated age groups to still include a sufficient number of participants.

Conclusion

The results of this study provide insights into an important aspect of the interaction between healthcare provider and PWE, namely how the provision of information regarding epilepsy is perceived by the patient, in terms of providing information about which the patient would like to know more, and the quality of the information provided, in the opinion of the recipient. We found that even in an epilepsy population in which 40% are seizure-free, there is a considerable need for relevant information. Whereas it seemed that the majority of patients were able to obtain information on general epilepsy issues, a much lower

proportion obtained information on non-medical treatments and psychosocial issues than those who wanted this information. As provision of relevant information according to patients' wishes should be a natural part of a comprehensive epilepsy care, and can be considered to be an important contribution towards patients' self-management strategies, our study indicates some issues on which patients would apparently like to be provided with more information than is currently the case.

Disclosure of Conflict of Interest

Oliver Henning has received speaker's honoraria from Eisai, UCB and Livanova. Morten Ingvar Lossius has been giving talks and participated in expert panels for Eisai and UCB. Kristin A. Alfstad and Karl Otto Nakken have no conflict of interest to disclose.

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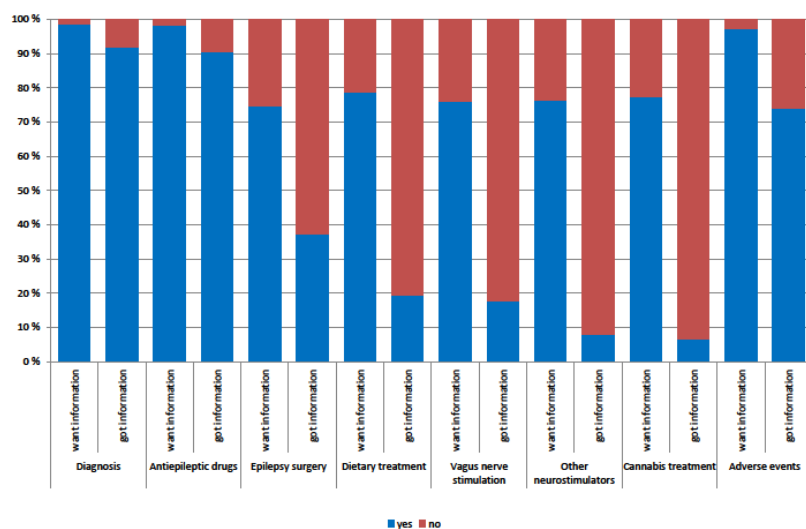


Figure 1a

Figure: 1a: Relative proportions of patients wanting and obtaining information on different issues related to diagnosis and treatment of epilepsy.

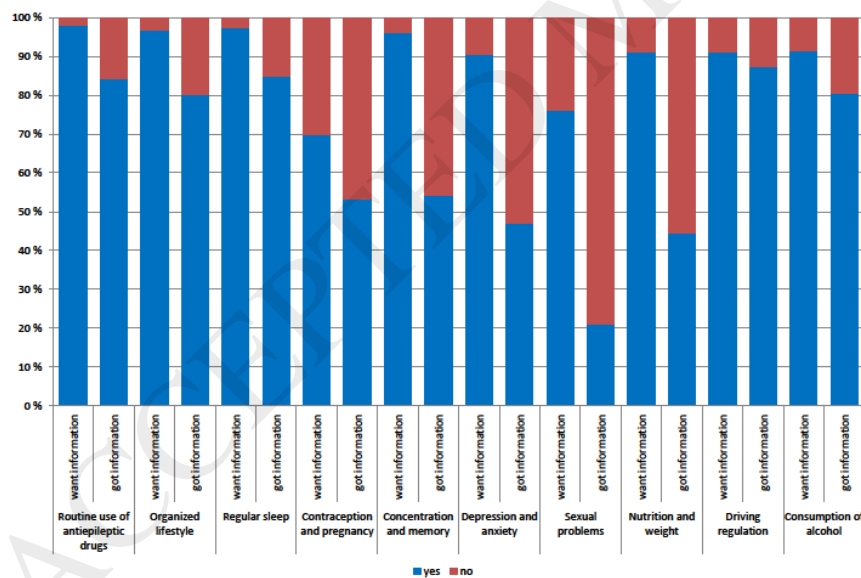


Figure 1b

Figure 1b: Relative proportions of patients wanting and obtaining information on different issues related to lifestyle and comorbidity in epilepsy.

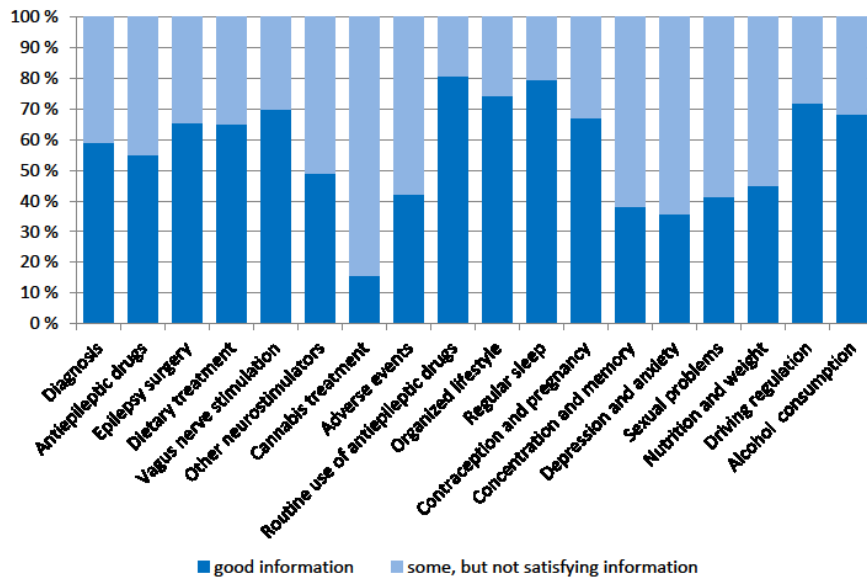


Figure 2

Figure 2: Relative proportions of patients obtaining good or insufficient information on different issues related to epilepsy.

Table 1: Demographic and clinical characteristics of the PWE participants (n=1182) in the survey

Table 1: Demographic and clinical characteristics of PWE (n=1182) participating in the survey

Characteristics	n (%)	Mean (max.-min.; standard deviation)
Age (years) ^a		41.8 (11-93; 14.92)
• 11-20 years	82 (7.1)	
• 21-30 years	228 (19.7)	
• 31-40 years	254 (22.0)	
• 41-50 years	267 (23.1)	
• 51-60 years	187 (16.2)	
• 61-70 years	103 (8.9)	
• Over 70 years	35 (3.0)	
Male gender ^b	372 (31.5)	
In a relationship ^c	697 (59.0)	
Age at first seizure (years) ^d		21.0 (1-80; 15.96)
Number of years with epilepsy ^e		20.4 (0-72; 16.10)
Seizure types ^f (multiple answers possible)		
• Focal, aware	346 (29.3)	
• Focal, impaired awareness	425 (36.0)	
• Tonic-clonic	719 (60.9)	
• Absences	263 (22.3)	
• PNES ^a	55 (4.7)	
• Other	86 (7.3)	
• Don't know	108 (9.1)	
Seizure-free throughout the previous year ^g	479 (40.6)	

PNES = Psychogenic non-epileptic seizures

^a1156/1182 answered, ^b1150/1182 answered, ^c1157/1182 answered, ^d1152/1182 answered, ^e1129/1182 answered, ^f1180/1182 answered, ^g1179/1182 answered,

Table 2: Different independent variables tested by multiple logistic regression analysis for association with dependent variables (having received information about different epilepsy-related issues).

Table 2. Different independent variables tested by multiple logistics regression for association to dependent variables (having received information about different epilepsy related issues).

Information subjects (dependent variables)	Independent variables	Odds ratios (OR), Confidence intervals (CI), probability
Diagnosis	Male gender	OR 0.830; CI:0.514-1.339; p=0.444
	Older than mean age	OR 0.811; CI:0.509-1.293; p=0.379
	Not being seizure free	X
	Having tonic-clonic seizures	OR 1.953; CI:1.231-3.100; p=0.005
Antiepileptic drugs	Male gender	OR 0.750; CI:0.489-1.151; p=0.188
	Older than mean age	X
	Not being seizure free	OR 0.728; CI:0.471-1.124; p=0.152
	Having tonic-clonic seizures	X
Epilepsy surgery	Male gender	OR 1.455; CI: 1.058-2.001; p=0.021
	Older than mean age	OR 1.566; CI:1.146-2.14; p=0.005
	Not being seizure free	OR 1.504; CI:1.095-2.066; p=0.012
	Having tonic-clonic seizures	OR 0.773; CI:0.565-1.057; p=0.107
Dietary treatment	Male gender	X
	Older than mean age	X
	Not being seizure free	OR 2.566; CI: 1.718-3.832; p<0.001
	Having tonic-clonic seizures	X
Vagus nerve stimulation	Male gender	OR 1.834; CI:1.240-2.711; p=0.002
	Older than mean age	OR 1.261; CI: 0.856-1.858; p=0.241
	Not being seizure free	OR 2.402; CI:1.550-3.721; p<0.001
	Tonic-clonic seizures	X
Other neurostimulation	Male gender	OR 1.868; CI:1.095-3.187; p=0.022
	Older than mean age	X
	Not being seizure free	OR 2.418; CI:1.282-4.559; p=0.006
	Tonic-clonic seizures	X

Cannabis treatment	Male gender	OR 1.813; CI:1.016-3.233; p=0.044
	Younger than mean age	OR 0.616; CI:0.338-1.124; p=0.114
	Being seizure free	OR 1.795; CI:0.938-3.435; p=0.077
	Having tonic-clonic seizures	X
Adverse events	Gender	OR 0.820; CI:0.605-1.112; p=0.202
	Younger than mean age	OR 1.351; CI:1.011-1.805; p=0.042
	Being seizure free	
	Having tonic-clonic seizures	
Routine use of AED	Gender	X
	Younger than mean age	X
	Being seizure free	OR 0.802; CI:0.568-1.134; p=0.212
	Having tonic-clonic seizures	OR 1.292; CI:0.923-1.808; p=0.135
Ordinary lifestyle	Gender	OR 1.257; CI:0.889-1.778; p=0.196
	Younger than mean age	OR 1.382; CI:1.000-1.909; p=0.050
	Being seizure free	X
	Having tonic-clonic seizures	OR 1.658; CI:1.204-2.283; p=0.002
Regular sleep	Gender	OR 0.814; CI:0.566-1.169; p=0.265
	Younger than mean age	OR 1.319; CI:0.926-1.876; p=0.124
	Being seizure free	X
	Having tonic-clonic seizures	OR 1.827; CI:1.290-2.588; p=0.001
Contraception and pregnancy	Female gender	OR 7.987; CI:5.155-12.346; p<0.001
	Younger than mean age	OR 2.160; CI:1.522-3.058; p<0.001
	Being seizure free	OR 1.488; CI:1.060-2.088; p=0.021
	Having tonic-clonic seizures	OR 1.170; CI:0.831-1.648; p=0.368
Concentration problems	Gender	X
	Younger than mean age	X
	Being seizure free	X
	Having tonic-clonic seizures	X
Depression	Gender	X
	Younger than mean age	X
	Being seizure free	OR 1.226; CI:0.947-1.588; p=0.121
	Having tonic-clonic seizures	X
Sexual problems	Gender	OR 1.398; CI:0.981-1.994; p=0.064
	Younger than mean age	X
	Being seizure free	X
	Having tonic-clonic seizures	X

Nutrition weight	Male gender	OR 1.495; CI:1.137-1.965; p=0.004
	Younger than mean age	X
	Being seizure free	OR 1.190; CI:0.915-1.547; p=0.195
	Having tonic-clonic seizures	X
Driving regulations	Gender	X
	Younger than age	X
	Being seizure free	OR 2.192; CI:1.449-3.311; p<0.001
	Tonic-clonic seizures	OR 1.424; CI:0.98-2.068; p=0.063
Alcohol consumption	Gender	OR 1.339; CI:0.930-1.927; p=0.116
	Younger than mean age	OR 0.798; CI:0.571-1.116; p=0.188
	Being seizure free	OR 1.692; CI:1.196-2.398; p=0.003
	Having tonic-clonic seizures	OR 1.661; CI:1.193-2.313; p=0.003

X No statistical significant association ($p < 0.25$) in the Pearson Chi-Square test and therefore not tested in the multivariate logistic regression analysis.

■ Statistical significant association in the Pearson Chi-Square test and in the multivariate logistic regression analysis.