



Patient satisfaction with information provided by epilepsy specialist nurses: Results of an online survey

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ABSTRACT

The aim of this study was to investigate the perspective of Norwegian patients with epilepsy regarding the information that they have received about epilepsy-related issues and to determine whether there was a difference in information received between those who had been followed up by an epilepsy specialist nurse (ESN) and those who had not. Further, were there differences regarding satisfaction with the information between the two groups?

We conducted an online survey in close collaboration with the Norwegian Epilepsy Association. A total of 1859 respondents (1182 patients with epilepsy and 677 carers for patients with epilepsy) completed a web-based questionnaire. They were asked about epilepsy-related issues on which they had received information, the extent to which they were satisfied with this information, and whether they were being followed up by an ESN or not. Significantly more patients followed up by an ESN had received information about the epilepsy diagnosis, antiseizure drugs (ASDs), routine use of ASD, and risk of seizure-related injuries as compared to those not followed up by an ESN. In addition, patients followed by an ESN were more likely to be satisfied with the information they received. Just above or under half of the respondents had received or were satisfied with information about depression, anxiety, premature death, and sexual wellbeing. Our results indicate that follow-up by ESNs results in improvements in the information provided to patients with epilepsy; ESNs should be an integral part of comprehensive epilepsy service.

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1. Introduction

Epilepsy is one of the most common neurological disorders, affecting about 65 million people worldwide [1]. In Norway, the prevalence is estimated to be 0.65% [2]. In addition to the main symptom (recurrent epileptic seizures), many patients with epilepsy struggle with comorbidities of neurological, cognitive, and/or psychosocial nature. Moreover, epilepsy is associated with an increased risk of discrimination, social isolation, and premature death. The care needs of this patient group are thus multifaceted, and treatment should aim not only at achieving seizure control, but also at addressing the many other associated negative consequences of epilepsy [3].

Up to 70% of patients with epilepsy achieve seizure control by tailored treatment with the antiseizure drugs (ASDs) that are currently available, but about 30% suffer from refractory epilepsy despite recent therapeutic developments [4,5]. One of the main challenges for the

future is achieving better understanding of the epilepsy mechanisms, thereby leading to potential new therapies to bridge the current treatment gap in the care of those with refractory epilepsy. Not only the people with epilepsy, but also their families, communities, and societies, are affected by the impact of the condition [3].

In order for people with epilepsy to be able to manage the many challenges associated with recurrent seizures, thorough information about the disease is of decisive importance [6–8]. Nurses specializing in epilepsy play a vital role in contributing to the quality of care of patients with epilepsy [9], and one of the main tasks of epilepsy specialist nurses (ESNs) is to provide information and advice about different epilepsy-related issues. This information should be revisited on subsequent consultations [6]. The ESNs should promote wider insights into the condition and should use a holistic, collaborative, and coordinated approach that can contribute towards reducing the impact of epilepsy [7].

The ESNs should be natural members of the multidisciplinary team treating patients with epilepsy, providing a variety of practical care as well as information and education regarding the diagnosis and the potential impacts of epilepsy [10]; ESNs can also support other nurses in providing information and advice [11].

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Both international and national recommendations emphasize the importance of improving access to health information and giving patients the opportunity to use the information more effectively. Health literacy has been described as each individual's skills in obtaining, understanding, and using health information [12]. Strengthening health literacy builds resilience and also improves health and quality of life [8,13–16]. Epidemiological studies have revealed that people with epilepsy are at risk of having low health literacy, with both income and education also being lower than that of the general population [17]. According to Paschal et al. [18], among parents of children with epilepsy, nearly two-thirds had inadequate and marginal health literacy.

It is generally agreed that when health information is provided, it should be tailored to the individual patient's ability to utilize the information and the patient's current situation, e.g., age, gender, culture, and stage of life [6–8,15]. As ESNs have special knowledge and skills regarding epilepsy care, they play a central role in the provision of health information to their patients. Guidelines in Great Britain describe the role of ESNs, and recommend that ESNs should be an integral part of the network of epilepsy care [6,7].

Few studies have investigated the patients with epilepsy viewpoint regarding the type and quality of information that they have received from healthcare providers [19–21], and it is of relevance to determine whether the information provided to patients by ESN is considered to be of value. Patients being followed up by ESNs have reported to have received better information and advice as compared those with ordinary medical follow-up [20,21]. However, they still wanted more information about nonmedical treatments and psychosocial issues [19].

Even in Norway, the qualification of ESNs varies. They all have a bachelor degree in nursing as minimum, and in addition, most of them have several years of experience from pediatric or neurological departments or epilepsy care units. Here, they work in close collaboration with the doctors.

The aim of this study was to investigate the perspective of Norwegian patients with epilepsy regarding the information that they have received about epilepsy-related issues. In particular, the intention was to determine whether there was a difference in information received between those who had been followed up by an ESN or those who had not, and also the extent to which the two groups of patients were satisfied with the information that they had received.

2. Material and methods

2.1. Patient recruitment

This study was based on a collaboration between the National Center for Epilepsy and the Norwegian Epilepsy Association (NEA). All visitors to NEA's homepage between April 2017 and September 2017 were guided to an online questionnaire regarding information received on epilepsy and epilepsy-related challenges. The NEA also advertised the survey in their periodical, and a link to the survey was available on their Facebook site. The survey was anonymous, and each participant could complete the questionnaire only once. The questionnaire could be answered by people with epilepsy or by caregivers, family members, or guardians who could answer on behalf of the person with epilepsy.

2.2. The questionnaire

The questionnaire was developed at the National Center for Epilepsy, in close collaboration with representatives from the NEA. This ensured that relevant questions were included in the questionnaire. Thus, we did not carry out a pilot study for validity. The complete questionnaire contained 56 questions, but this study was based only on a few of these questions. Results of other parts of the project have been published elsewhere [19,22–25].

The questionnaire covered different sets of questions. These included background information (the patient's epilepsy type, current

treatment, and how they were followed up), the information that they had received about different epilepsy-related issues as listed in Table 2, and the extent to which they were satisfied with the information received. All respondents were also asked whether they had been followed up by an ESN.

The answer options were the following alternatives for each of question: "No information", "Some information, but want more", "Yes, good information", "I do not remember", or "Do not want information/not relevant".

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 the following: "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 the following: "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".

"Missing" refers to those who did not clarify by whom they had been followed up. "Known/unknown" etiology refers to what is reported by the respondents.

2.3. Statistical methods

The IBM SPSS Statistics, version 25, release 25.0.0.1. (SPSS Inc) was used for statistical analyses. Continuous variables were expressed as the mean and standard deviation (SD); categorical data were expressed as counts and proportions. Possible group differences between those followed up by ESN and those without such follow-up were tested by chi-square tests and *t*-tests for categorical and continuous variables, respectively. All *p*-values presented here are based on two-sided tests, with a significance level of 0.05. A Bonferroni correction was done to correct for multiple comparisons.

2.4. Ethical aspects

The study was performed in accordance with the declaration of Helsinki and approved by the Regional Ethics Committee (ref.no.:2017/563) prior to implementation. Visitors to the homepage of NEA were well informed about the aim of the study and that participation was fully voluntarily. The participants were ensured anonymity, and that no internet protocol (IP) address was stored. We informed the participants that by opening the survey they gave their consent to participation.

3. Results

During the study period, the NEA's website had 48,249 visitors. In total, 1859 respondents (1182 patients with epilepsy and 677 carers) filled in the questionnaire. Not all respondents answered all questions, so questionnaires were either partly or fully completed.

3.1. Demographic and clinical characteristics

Of a total of 1846 respondents, 73.6% were followed up by a neurologist or a pediatrician, and 28.1% reported follow-up by a general practitioner. Both specialist and general practitioner follow-up were reported by 18.2%. Among all respondents, 265 (14.4%) reported additional follow-up by an ESN. Those respondents who had been followed up by an ESN were significantly younger than those not followed up by an ESN (mean age: 25.9 years vs. 33.7 years, respectively; $p < .001$). Moreover, the group reporting followed up by an ESN had significantly more frequent seizures, and there was a trend towards this group being

more likely to report knowledge about their epilepsy etiology. Significantly more of the respondents who had additional follow-up by an ESN reported living alone (Table 1).

3.2. Information received

Among those patients followed up by an ESN, after Bonferroni correction statistically significantly more had received information about diagnosis ($p = .002$), ASDs ($p = .002$), routine use of ASDs ($p < 0.001$), and risk of injuries ($p = .002$) than those not followed up by an ESN (Table 2).

No statistically significant association was found with ESN follow-up and receiving information on the topics of epilepsy surgery, other neurostimulation, cannabis treatment, premature death, contraception/pregnancy, depression and anxiety, sexual problems, driving regulations, and consumption of alcohol (Table 2).

When doing a subgroup analysis among respondents under and above 18 years of age, we found a significant higher degree of respondents under age 18 having been followed up by ESN to be informed about the following issues: driving regulations ($p = .001$), risk for injuries ($p = .002$), concentration/memory ($p = .003$), contraception/pregnancy ($p = .01$), adverse drug events ($p = .022$), consumption of alcohol ($p = .042$), and nutrition and weight ($p = .046$). After Bonferroni correction, information about driving regulations, risk for injuries and concentration/memory problems remain statistically significant. A significant higher degree of respondents above age 18 having been followed up by ESN reported to be informed about the following issues: routine use of ASDs ($p < .001$), ASDs ($p < .001$), and diagnosis ($p = .006$). After Bonferroni correction, information about routine use of ASDs and ASDs remain statistically significant.

We performed an additional subgroup analysis looking at patients who had or had not been followed up by a specialist (neurologist/pediatrician). We found that among those who had not been followed up by a specialist, significantly more had follow-up by ESN and reported to have been informed about the following issues: adverse drug events ($p = .001$), risk for injuries ($p = .001$), ASDs ($p = .002$), concentration/memory problems ($p = .002$), vagus nerve stimulator ($p = .028$), and regular sleep pattern ($p = .040$). After Bonferroni correction, adverse drug events, risk for injuries, ASDs, and concentration/memory problems remain statistically significant.

Table 1

Demographic and clinical characteristics of the participants who 1) were followed up by an epilepsy nurse (ESN; $n = 265$) and 2) who were not followed up by an ESN ($n = 1581$).

Characteristics of the participants	Followed up by an ESN	Not followed up by an ESN
Mean age (SD, range) (years) ^a	25.9 (15.8, 0–70) ***	33.7 (18.9, 0–93)
Male gender, n (%) ^b	99 (38.1)	623 (40.2)
Living alone, n (%)	^c 175 (67.3) ***	848 (55.2)
Married/cohabiting, n (%) ^c	58 (22.3)	580 (37.8)
In a relationship, n (%) ^c	27 (10.4)	107 (7.0)
Seizure-free the previous year, n (%) ^d	78 (29.5)	551 (35.0)
Daily/weekly seizures, n (%) ^e	89 (48.9) *	390 (39.3)
Monthly/more seldom seizures, n (%) ^e	93 (51.1) *	603 (60.7)
Known epilepsy etiology, n (%) ^f	119 (45.2)	683 (43.4)
Unknown epilepsy etiology, n (%) ^f	91 (34.6)	891 (56.6)
Medical follow-up at least annually, n (%) ^g	238 (90.2)	1020 (87.7)

* $p \leq .05$ ** $p \leq .01$, *** $p \leq .001$.

ESN = Epilepsy specialist nurse.

^a $n = 1812$.

^b $n = 1813$.

^c $n = 1799$.

^d $n = 1845$.

^e $n = 1178$.

^f $n = 1842$.

^g $n = 1427$.

Table 2

Topics on which patients had received information, according to follow up by 1) an ESN (epilepsy specialist nurse; $n = 265$), and 2) those not followed up by an ESN ($n = 1594$).

Topic	Patients reporting they had received information n (%)		p value
	Follow-up by ESN	No follow-up by ESN	
Diagnosis ($n = 1702$)	246 (98.4)	1354 (93.3)	0.002*
Antiseizure drugs (ASDs; $n = 1696$)	243 (96.8)	1318 (91.2)	0.002*
Epilepsy surgery ($n = 1217$)	75 (41.9)	385 (37.1)	0.220
Dietary treatment ($n = 1320$)	65 (34.4)	276 (24.4)	0.004
Vagus nerve stimulation ($n = 1261$)	50 (27.9)	234 (21.6)	0.061
Other neurostimulant ($n = 1261$)	13 (7.3)	85 (7.7)	0.836
Cannabis treatment ($n = 1305$)	11 (5.9)	72 (6.4)	0.772
Adverse drug events ($n = 1661$)	204 (84.3)	1086 (76.5)	0.007
Routine use of ASDs ($n = 1655$)	229 (95.0)	1212 (85.7)	<0.001*
Organized lifestyle ($n = 1639$)	212 (88.3)	1149 (82.1)	0.018
Regular sleep pattern ($n = 1687$)	228 (90.8)	1242 (86.5)	0.058
Risk of injuries ($n = 1530$)	187 (82.4)	949 (72.8)	0.002*
Premature death ($n = 1511$)	81 (36.3)	412 (32.0)	0.202
Contraception/pregnancy ($n = 1008$)	79 (54.1)	419 (48.6)	0.219
Concentration/memory ($n = 1575$)	162 (69.2)	807 (60.2)	0.009
Depression/anxiety ($n = 1458$)	117 (55.2)	633 (50.8)	0.238
Sexual problems ($n = 1040$)	35 (23.0)	187 (21.1)	0.584
Nutrition and weight ($n = 1526$)	135 (59.5)	644 (49.6)	0.006
Driving regulations ($n = 1390$)	165 (85.5)	968 (80.9)	0.125
Consumption of alcohol ($n = 1337$)	147 (77.8)	874 (76.1)	0.622

Abbreviations: ASD = Antiseizure drug, ESN = Epilepsy specialist nurse.

p-values describe statistically significant differences between the groups using Pearson's chi-square.

* Significant after Bonferroni correction.

3.3. Satisfaction with information received

Those respondents that had been followed up by an ESN were after Bonferroni correction significantly more likely to be satisfied with the information that they had received about the diagnosis ($p = .002$), sleep patterns ($p = .002$), and concentration and memory problems ($p < .001$) than those not who had not been followed up by an ESN (Table 3). Of those not followed up by an ESN, a higher percentage was satisfied with the information that they had received about epilepsy surgery, dietary treatment, vagus nerve stimulation, and contraception and pregnancy.

4. Discussion

The main finding in this study, which included more participants than most similar studies, is that those who had received additional follow-up by an ESN were better informed about several epilepsy-related topics than those with regular medical follow-up. There might be many reasons for this.

Compared to medical doctors, ESNs may allocate more time to individualized patient education and thereby facilitate their own coping strategies and increase health literacy. Health information is often given in a written format, but the language used frequently exceeds the recommended 6th–8th grade level and is therefore not appropriate for people with low health literacy [17]. As opposed to many medical doctors, ESNs may avoid medical terms and provide information in a simple language [26].

In addition to being satisfied with the information they also experienced practical and emotional support as in other studies [20,27]. The ESNs may increase health literacy in a better way than medical doctors. Assuming that there is an association between improved understandings (greater health literacy) and coping with epilepsy, follow-up by ESNs may thus result in a better health outcome for these patients.

Shared decision-making require high-quality information [28]. According to the International Council of Nurses, nurses should be skilled and authorized to provide relevant health information [29]. Health

Table 3

Satisfaction with information received among respondents: comparison between those followed up by epilepsy specialist nurse (ESN; n = 265) and those not followed up by an ESN (n = 1594).

Patients satisfied with the information provided n (%)			
Topic	Follow-up by ESN	No follow-up by ESN	p value
Diagnosis (n = 1600)	167 (67.9)	779 (57.5)	0.002*
Antiseizure drugs (ADS; n = 1561)	152 (62.6)	710 (53.9)	0.012
Epilepsy surgery (n = 460)	46 (61.3)	260 (66.5)	0.389
Dietary treatment (n = 341)	39 (60.0)	183 (66.3)	0.337
Vagus nerve stimulation (n = 284)	34 (68.0)	165 (70.5)	0.725
Other neurostimulant (n = 98)	9 (69.2)	39 (45.9)	0.117
Cannabis treatment (n = 83)	1 (9.1)	12 (16.7)	0.520
Adverse drug events (n = 1290)	102 (50.0)	440 (40.5)	0.012
Routine use of ASD (n = 1441)	199 (86.9)	964 (79.5)	0.010
Organized lifestyle (n = 1361)	170 (80.2)	842 (73.3)	0.034
Regular sleep (n = 1470)	199 (87.3)	973 (78.3)	0.002*
Risk of injuries (n = 1136)	134 (71.7)	633 (66.7)	0.186
Premature death (n = 493)	46 (56.8)	203 (49.3)	0.216
Contraception/pregnancy (n = 498)	48 (60.8)	286 (68.3)	0.193
Concentration/memory (n = 969)	83 (51.2)	288 (35.7)	<0.001*
Depression/anxiety (n = 750)	47 (40.2)	22 (35.1)	0.291
Sexual problems (n = 222)	17 (48.6)	75 (40.1)	0.351
Nutrition and weight (n = 779)	69 (51.1)	281 (43.6)	0.112
Driving regulations (n = 1133)	122 (73.9)	692 (71.5)	0.517
Consumption of alcohol (n = 1021)	108 (73.5)	589 (67.4)	0.143

Abbreviations: ASD = Antiseizure drug, ESN = Epilepsy specialist nurse.

p-values describe statistically significant differences between the groups using Pearson's chi-square.

* Significant after Bonferroni correction.

literacy is an issue of communication [14]. However, many healthcare workers are apparently unaware of patients' low levels of health literacy, and many patients report being too embarrassed to admit that they do not understand the health information with which they are provided [14]. The ESNs should be able to assist patients in developing the necessary skills to access, understand, and use health information [13].

4.1. Epilepsy etiology, severity, age, and medication

Those followed up by ESNs reported to be better informed about the epilepsy etiology than those with ordinary medical follow-up. This is in agreement with previous studies showing that those followed up by ESNs claimed to be well informed about causes and types of epilepsy [20,30].

Young people with severe epilepsy may be in greater need of information than others with epilepsy due to less experience [14]. This might explain why we found that those who had additional follow up by an ESN were significantly younger and had more frequent seizures than those with ordinary medical follow-up. Higgins et al. [20] also found that participants with follow-up by ESN had a younger profile in comparison with those not followed up by ESN. However, also patients with infrequent seizures might benefit from consultation with an ESN [31].

A recent German study revealed that young age was one of the most important predisposing factors associated with nonadherence to prescribed treatment regimens [32]. Hence, nonadherent patients should be identified, and reasons for nonadherence should be explored. Both unintentional and intentional nonadherence should be addressed, and tailored interventions ought to be implemented [23,32]. By emphasizing the importance of regular drug intake, ESNs may improve medication adherence [33].

Information about the diagnosis and ASDs was reported significantly more frequently, and the patients were significantly more satisfied with the information about diagnosis, in the group followed up by ESNs. Significantly more patients with follow-up by ESN but not by specialist (neurologist/pediatrician) had been informed about ASD and adverse drug events. There was a tendency towards more patients followed up

by ESN having received information about adverse drug events, and they were more satisfied with the information. The finding regarding adverse drug effects concur with some previous studies [20,33,34]. During hospitalization, nurses are in charge of dispensing the prescribed medication to the patients, and this creates a natural situation for providing thorough information about ASDs and the most common adverse events. Mills et al. claim that patients perceived that doctors lack time and emphasize drug monitoring more the thorough information [21]. Helde et al. reported increased treatment adherence among patients followed up by ESNs, possibly because of better information about the condition [35].

4.2. Cognitive challenges

Those followed up by ESNs were significantly more likely to have received information about cognitive problems, i.e., concentration and memory failure. They were also more satisfied with the received information about this topic. Significantly more patients with follow up by ESN but not by specialist (neurologist/pediatrician) had been informed about concentration and memory failure. However, only 60–70% reported to have received information on this topic, and fewer than half the respondents were satisfied with the information. Considering the high prevalence of cognitive problems in this group [22], it is obviously a potential for improvement in information about these issues, also among ESNs.

The ESNs should ensure adequate time to provide thorough information and to repeat information from earlier consultations to ensure that the information is remembered and understood [6,7].

4.3. Lifestyle and risk of injuries

Our impression is that many people with epilepsy may impose unnecessary restrictions on their lifestyles due to fear of seizures or seizure-related injuries. As patients in our survey that had been followed up by an ESN were better informed about how to live with epilepsy, it seems that this may be one way to address attitude matters.

A significantly higher proportion of patients followed up by ESNs had received information on the risk of injuries. Higgins et al. [20] found that patients attending services with an ESN had received more information about safety aspects of epilepsy. Among respondents followed up by ESN and not follow up by a specialist (neurologist/pediatrician) significantly more of these have been informed on risk of injuries. The patients should be assured that seizure-related injuries occur far more seldom than many think [36], and ESNs may educate them about seizure-precipitating factors and help them to remove unnecessary restrictions in their lifestyle [10].

4.4. Depression and anxiety

People with epilepsy report lower levels of both mental and physical health than people with other chronic diseases [37]. In particular, depression and anxiety are frequently occurring [3,22,38]. Depression and anxiety may exacerbate seizure susceptibility and may even reduce quality of life more than the seizures themselves [3]. Among our respondents, just above half had received information about depression and anxiety, and less than half was satisfied with this information. On this topic, we found no difference between those followed up by ESNs or not.

Some previous studies have revealed that those followed up by ESNs had a lower risk of depression and an improved emotional wellbeing [30,33]. However, one study disclosed lack of knowledge among ESNs regarding serious mental health morbidities [10,26]. Our findings indicate that psychiatric comorbidities need to be further highlighted by ESNs, and their competence on these issues needs to be strengthened.

4.5. Specific issues

Although people with epilepsy are at increased risk of premature death [3], less than 50% of our respondents in both groups had received information on this subject. This concurs with previous research showing that information on premature death is sparse [26]. However, it is now acknowledged that counseling about the risks of sudden unexpected death in epilepsy should be provided at an appropriate time and individualized, taking into account the patients' risk profile. This issue should be given more attention by the epilepsy community [7].

In our survey, less than half of the respondents had received information about sexual problems, and less than half were satisfied with this information. There was no significant difference between our two groups. According to Henning et al., people with epilepsy report a significantly higher degree of sexual problems than the general adult population [39].

We suggest that ESNs should allocate more time for providing information about specific issues like premature death and sexual problems.

4.6. Subgroups age

By doing a subgroup analysis, we found differences between respondents under and over age 18 concerning received information about epilepsy-related issues. Among respondents under the age of 18 followed up by ESN, we found a significant higher degree of respondents reported being informed about driving regulations, risk of injuries, concentration/memory, contraception/pregnancy, drug adverse events, consumption of alcohol, and nutrition and weight. Only driving regulations, risk of injuries and concentration/memory remain statistically significant after Bonferroni correction.

Respondents over the age of 18 followed up by ESN were significantly better informed about routine use of ASD, ASD, and diagnosis. After Bonferroni correction only the topic ASD and routine use of ASD remain statistically significant. Helde et al. [35] also found that follow up by ESN resulted in improvement on the topic medication effects. According to Higgins et al. [20], follow-up by ESN patients had statistically significant higher mean scores in terms of information provided on medical aspects.

4.7. The role of ESN

At the National Center for Epilepsy in Norway, ESNs are responsible for coordinating patient education [40]. It has been shown that Norwegian patients with epilepsy needs for information are only partially met by healthcare providers [19]. Within a framework of a holistic and patient-centered care, ESNs, in close collaboration with patients, their families, and other health professionals, should provide evidence-based information about achieving the best possible life with epilepsy.

In our opinion, ESNs are well positioned to support patients with self-management and to cope with the various epilepsy-related challenges [20]. Nevertheless, there is paucity of evidence-based research about the role of ESNs in the care for people with epilepsy and their impact on service outcomes. An Irish study showed that ESNs may have a positive impact on the lives of people with epilepsy by enhancing their knowledge and confidence regarding self-care [20,26]. Studies of the role of ESNs have only been performed in some developed countries, and one should be cautious about generalizing these findings.

A structured pathway for ESNs and their progression in specialist nursing is necessary, along with government recognition [41]. Currently, there is no generally accepted systematic education for ESNs [10], although a variety of organizations have made efforts to enhance education of nurses in epilepsy care [10]. In our opinion, the role of ESNs should be improved globally, and all people with epilepsy should have access to ESN services. In addition, ESNs can be a useful link

between different levels in the healthcare system [30,35,42,43]. Although ESN is currently not an approved title by Norwegian health authorities, ESNs are currently an integrated part of the health service in many Norwegian hospitals.

4.8. Limitations of the study

During the study period, nearly 50,000 unique users visited the website of the NEA. This represents about 1% of Norway's population. Only about 4% of visitors to the homepage responded to the questionnaire. This might indicate a selection bias as we do not have any information about those who did not participate.

When searching for epilepsy on the Norwegian Google site, the homepage of NEA is the first site listed. Thus, visitors to NEA's homepage could be anyone in Norway looking for information about epilepsy. However, respondents to the questionnaire may have had more severe epilepsies than on average, as only about one third of the respondents reported to be seizure-free. In a general Norwegian population with epilepsy, one would expect two-thirds to be seizure-free. There is also a potential selection bias towards participants with greater need for information than the "average" patient with epilepsy.

Other limitations are the known problems with validity of questionnaires based on close-ended questions. As we have no details regarding the information actually given to the respondents, there might be a recall bias. This is also the case regarding the quality of information. As the survey was online and only available in Norwegian language, people without internet access or not reading Norwegian would have been unable to participate in the study.

The role of ESN varies, and their expertise depends upon their education and experience [7]. We have no knowledge concerning the background of the different ESNs to whom the patients referred, and this probably had an impact on their provision of information.

5. Conclusions

Our findings suggest that additional follow-up by ESNs results in patients receiving improved information on several epilepsy-related issues. However, there are still areas of information that need to be improved. The ESNs should facilitate good communication between the patient and the healthcare system, and, by helping patients with epilepsy to obtain, process, and understand relevant health information, have a role in improving comprehensive epilepsy care.

Declaration of competing interest

Nann Christin Ek Hauge, Karl Otto Nakken, and Heidi Bjørge have no conflicts of interest to disclose. Oliver Henning has served as a paid consultant for Eisai, UCB and LivaNova, outside the submitted work.

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