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Challenges in epilepsy—The perspective of Norwegian epilepsy patients

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Objectives: For most people with epilepsy (PWE), problems that are not directly related to seizures may constitute major challenges in everyday life. The purpose of this study was to determine the extent of these challenges and any risk factors for their occurrence among PWE in Norway, based on the patients' own perspective.

Materials and Methods: We used a web-based survey to ask PWE visiting the homepage of the Norwegian Epilepsy Association about different everyday challenges. A link to the survey was accessible via the members' homepage for a 4-month period during 2017.

Results: One thousand one hundred eighty-two PWE responded to the questionnaire. Although more than 40% of the cohort reported that they had been seizure free for at least 1 year, the majority reported that tiredness (71%), memory problems (70%), concentration problems (68%), headache or vertigo (51%), and feeling depressed (59%) continued to represent challenges. In addition, fear of being alone, sexual problems or difficulties in social settings were reported by about one-third of the patients. Reporting having these challenges was significantly associated with female gender, polytherapy, experiencing seizures during the previous 12 months and feeling blue or depressed.

Conclusions: The results of this study, reflecting a self-selected Norwegian population, provide insights into the challenges not directly associated with seizures that impact on the quality of life of PWE. The impacts of such challenges may be underestimated as components of the entire burden of epilepsy.

KEYWORDS
challenges, epilepsy, quality of life, treatment

1 | INTRODUCTION

Epilepsy is one of the most common neurological disorders with a prevalence of about 0.7%.[1-3] Medication with antiepileptic drugs (AEDs) is the cornerstone of epilepsy treatment, and almost 70% of patients become seizure free with appropriate AED therapy.[4] Nevertheless, even among seizure-free patients, the disease may have an adverse impact on daily activities and feeling of well-being. This is reflected in the definition of epilepsy proposed by International League Against Epilepsy (ILAE) in 2005, in which epilepsy was defined as an enduring predisposition to generate epileptic seizures and by neurobiological, cognitive, psychological and social consequences of the condition.[5] By including the consequences of the disease in their definition, ILAE emphasized that the consequences of epilepsy encompass far more than seizures.[5]

Due to the unpredictability of seizures, many patients have a constant fear of them occurring, even if there has been a prolonged period of being seizure free.[6] Moreover, some PWE may experience chronic adverse effects from the AED or other treatment, and the disorder may present obstacles to education, work, driving, establishing a family, and development and maintenance of social relationships. In addition, epilepsy may adversely affect an individual's self-esteem and self-image.[6-9]

Data on how people with epilepsy (PWE) perceive their daily challenges are available from various studies.[6,9-13] Questionnaires used to evaluate quality of life like the QOLIE-31 do to some degree also cover similar aspects.[14] They are often used in various populations.[15] The aim of this study was to use an online survey among a self-selected Norwegian population to determine the extent to which PWE experience challenges not directly related to seizures, but that impact on their quality of life. Awareness of this problem may contribute to more comprehensive patient care. It might help to consider patients' needs by providing information and measures for improved quality of life.

2 | MATERIAL AND METHODS

2.1 | Study population

This study was a collaboration between the National Epilepsy Centre in Norway and the Norwegian Epilepsy Association (NEA), the organization for patients with epilepsy in Norway. From 1 April to 5 September 2017, all visitors to NEA's homepage were guided to an online questionnaire regarding epilepsy and epilepsy-related challenges. Information about the survey and a link to it were also available via the Facebook site of NEA. The target population included all PWE who visited the website. Each participant could complete the questionnaire only once.

2.2 | The electronic questionnaire

The survey was anonymous. The questions were closed-ended and were decided following thorough discussion with experts at the National Epilepsy Centre and advisors at NEA. The questionnaire consisted of 42 questions. Completion of the questionnaire was estimated to take approximately 15-20 minutes.

Questions in the first part of the questionnaire were designed to elicit background information on the PWE (eg, gender, age group, being in a relationship) and also covered the patient's epilepsy (type, duration, age at first seizure and current seizures), treatment and follow-up. Respondents were then asked about whether quality of life was affected by a variety of different challenges. These included fear of having a seizure, fear of being alone, problems with concentration and/or memory, feeling down/blue and/or depressed, sexual problems, difficulties with physical activities, transport problems, physical symptoms such as drowsiness, headache, and/or vertigo and having difficulties with social interactions.

The answer options were based on a modified Likert scale, with the possibilities: "not at all"; "to a lesser degree"; "somewhat"; and "to a considerable extent." In further analysis of the questionnaires, the answers were dichotomized to either "not at all and to a lesser degree" vs "somewhat and to a considerable extent." This dichotomization was done according to the clinical relevance the different challenges pose to patients and physicians.

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

The data that support the findings of this study are available from the corresponding author upon reasonable request.

2.3 | Statistical analyses

IBM SPSS Statistics version 25, release 25.0.0.1. (SPSS Inc) 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. Odds ratios for predictors for perceived challenges were estimated using bivariate and multivariate logistic regression analyses.

Variables tested were gender, use of polytherapy (two or more AEDs), above or below the mean age of the participants, known epilepsy aetiology, having tonic-clonic seizures, having been seizure free for the previous 12 months, feeling blue/down or depressed and being in a relationship. Feeling down/blue or depressed was not tested as a variable for fear of being alone, problems with concentration and/or memory and tiredness as these challenges may not to be independent.

3 | RESULTS

3.1 | General aspects

The NEA website recorded 48 249 visits during the study period, and 1182 PWE participated in the survey. Not all participants answered all questions. Demographic and clinical characteristics of the participants are summarized in Table 1. More than 40% of respondents reported being seizure free in the previous year.

The majority (>50%) of respondents reported that their quality of life was reduced, somewhat or to a considerable extent, by tiredness, memory and concentration problems, feeling down/blue and/or depressed, and by headaches and/or vertigo. About 30% reported fear of being alone, sexual problems and difficulties in social interactions (Figure 1). Responses to the main categories of symptoms and reports are presented below.

3.2 | Cognitive problems

Cognitive problems like memory (70%, n = 811/1157) and concentration (68%, n = 779/1153) problems were among the predominate challenges reported by a large majority of the patients (Figure 1).

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

Characteristics	Response to specific question n (%)	n (%)	Mean (range)
Age (y)	1156 (97.8)		41.8 (11-93)
Male gender	1150 (97.3)	372 (31.5)	
In a relationship	1157 (97.9)	697 (59.0)	
Living together with others	1146 (97.0)	782 (68.2)	
Age at first seizure (y)	1152 (97.5)		21.0 (1-80)
Number of years with epilepsy	1129 (95.5)		20.4 (0-72)
Seizure types	1180 (99.8)		
Focal, aware		346 (29.3)	
Focal, impaired awareness		425 (36.0)	
Tonic-clonic		719 (60.9)	
Absences		263 (22.3)	
PNES		55 (4.7)	
Other		86 (7.3)	
Do not know		108 (9.1)	
Seizure-free throughout the previous year	1179 (99.7)	479 (40.6)	
Seizure frequency	674 (57.0)		
Daily/weekly		211 (31.3)	
Monthly/more seldom		463 (68-7)	
Epilepsy aetiology	1174 (99.3)		
Known		543 (46.3)	
Unknown		631 (53.7)	
Monotherapy	1074 (90.9)	597 (55.6)	
Medical follow-up at least once per year	850 (71.9)	708 (83.3)	

Abbreviation: PNES, Psychogenic non-epileptic seizures.

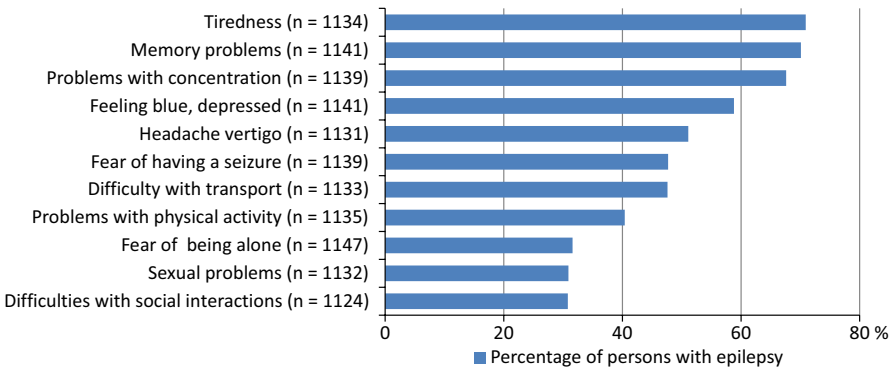

FIGURE 1 Challenges perceived by patients (n = 1183) somewhat/to a large degree in %

Multivariate logistic regression analysis indicated that female gender and not being seizure free were independent variables associated with perceived cognitive problems. Polytherapy was associated with memory problems, but not with concentration problems (Table 2).

3.3 | Medical problems

Participant reported medical problems like tiredness (71%, n = 826/1165) and headache or vertigo (51%, n = 590/1154) (Figure 1). Multivariate logistic regression analysis indicated that female gender and not being seizure free were among independent variables associated with perceived medical problems (Table 2).

3.4 | Psychosocial problems

Participants reported psychosocial problems like feeling blue or depressed (59%, n = 677/1151), fear of having a seizure (48%, n = 551/1156), sexual problems (31%, n = 352/1139), fear of being alone (32%, n = 362/1147) and difficulties in socializing with others

TABLE 2 Columns showing different independent variables as factors associated with reported perceived life challenges (dependent variables) shown in rows

Independent variables	Gender	Monotherapy vs polytherapy	Younger vs older than the mean age	Known vs unknown aetiology	Having vs not having tonic-clonic seizures (TCS)	Being vs not being seizure free the last 12 mo	Feeling blue, depressed	Being vs not being in a relationship
Dependent variables								
Fear of being alone	Female gender OR 1.599; CI: 1.169-2.188; *P* = 0.003		Younger than mean age OR 1.597; CI: 1.186-2.155; *P* = 0.002		Having TCS OR 1.429; CI: 1.060-1.925; *P* = 0.019			
Problems with concentration	Female gender OR 1.991; CI: 1.495-2.650; *P* < 0.001				Having TCS OR 1.384; CI: 1.043-1.837; *P* = 0.024	Not seizure free OR 1.470; CI: 1.108-1.952; *P* = 0.008		
Feeling blue, depressed	Female gender OR 1.339; CI: 1.016-1.765; *P* = 0.038	Polytherapy OR 1.408; CI: 1.077-1.841; *P* = 0.012			Having TCS OR 1.309; CI: 1.000-1.713; *P* = 0.050	Not seizure free OR 1.436; CI: 1.099-1.878; *P* = 0.008		
Memory problems	Female gender OR 1.906; CI: 1.421-2.558; *P* < 0.001	Polytherapy OR 1.546; CI: 1.151-2.076; *P* = 0.004				Not seizure free OR 1.790; CI: 1.340-2.390; *P* < 0.001		Being in a relationship OR 1.387; CI: 1.035-1.858; *P* = 0.028
Sexual problems			Older than mean age OR 1.744; CI: 1.247-2.438; *P* = 0.001	Known aetiology OR 1.463; CI: 1.095-1.955; *P* = 0.010			Feeling blue, depressed OR 2.973; CI: 2.174-4.066; *P* < 0.001	Being in a relationship OR 1.598; CI: 1.175-2.173; *P* = 0.003
Problems with physical activity					Having TCS OR 1329; CI: 1.002-1.762; *P* = 0.049	Not seizure free OR 1.450; CI: 1.094-1.922; *P* = 0.010	Feeling blue, depressed OR 2.926; CI: 2.210-3.872; *P* < 0.001	
Difficulty with transport		Polytherapy OR 1.511; CI: 1.152-1.983; *P* = 0.003				Not seizure free OR 2.281; CI: 1.728-3.011; *P* < 0.001	Feeling blue, depressed OR 2.096; CI: 1.599-2.747; *P* < 0.001	
Headache, vertigo	Female gender OR 2.229; CI: 1.674-2.967; *P* < 0.001					Not seizure free OR 1.404; CI: 1.066-1.849; *P* = 0.016	Feeling blue, depressed OR 2.354; CI: 1.797-3.083; *P* < 0.001	

(Continues)

TABLE 2 (Continued)

Independent variables	Gender	Monotherapy vs polytherapy	Younger vs older than the mean age	Known vs unknown aetiology	Having vs not having tonic-clonic seizures (TCS)	Being vs not being seizure free the last 12 mo	Feeling blue, depressed	Being vs not being in a relationship
Difficulties with social interactions		Polytherapy OR 1.384; CI: 1.027-1.866; $P = 0.033$					Feeling blue, depressed OR 4.733; CI: 3.386-6.616; $P = 0.000$	Not being in a relationship OR 1.457; CI: 1.078-1.972; $P = 0.014$
Fear of having a seizure	Female gender OR 1.687; CI: 1.264-2.251; $P < 0.001$		Younger than mean age OR 1.779; CI: 1.328-2.386; $P < 0.001$	Unknown aetiology OR 1.355; CI: 1.035-1.773; $P = 0.027$			Feeling blue, depressed OR 2.477; CI: 1.886-3.254; $P < 0.001$	
Tiredness	Female gender OR 1.608; CI: 1.197-2.160; $P = 0.002$	Polytherapy OR 1.376; CI: 1.024-1.850; $P = 0.034$	Younger than mean age OR 1.574; CI: 1.132-2.192; $P = 0.007$			Not seizure free OR 1.589; CI: 1.188-2.124; $P = 0.002$		

■Significantly associated ($P < 0.05$). □Not significant ($P \geq 0.05$). ▨Variable not independent with regards to reported challenges (dependent variables).

(31%, n = 354/1149) (Figure 1). Multivariate logistic regression analysis indicated that feeling down/blue or depressed was strongly associated with all other psychosocial problems, apart from fear of being alone, which was not tested due to the possibility of overlap. Results regarding whether other variables were associated with psychosocial problems were inconsistent (Table 2).

3.5 | Physical limitations

Participants reported physical limitations like problems with transportation (48%, n = 550/1156) and difficulties with physical activities (40%, n = 466/1153) (Figure 1).

Multivariate logistic regression analysis indicated that feeling down/blue and/or depressed and not being seizure free were the independent variables associated with the different categories of physical limitations (Table 2).

4 | DISCUSSION

The main finding from this study was that most PWE in Norway experience several considerable everyday challenges that affect their quality of life. These challenges include cognitive and psychosocial problems, in addition to physical limitations. Our sample was recruited from persons visiting the homepage of the Norwegian Epilepsy Association, thus representing a selected group searching for information.

Although 40% of the participants in our cohort reported being seizure free for at least a year, most reported challenges with cognitive difficulties and, to a lesser extent, psychosocial problems and physical limitations. This information should serve as a reminder to healthcare providers working with PWE that the focus should not be solely on seizures, but that these additional challenges should also be included in healthcare plans.

4.1 | Cognitive problems

Cognitive problems, like memory problems and problems with concentration, were reported by about 70% of patients in this study, which is in line with results from other studies.

The high prevalence of memory problems in our study cohort is similar to that reported from other studies.[16] In a large community-based questionnaire survey among PWE in the United States (n = 1023), between 40% and 50% of respondents reported that epilepsy affected their ability to think clearly, to remember, to concentrate, and their mental and emotional well-being.[6] The possible causes of memory problems in PWE are complex and potentially multi-factorial. They may be related to dysfunction in the networks required for storage and or retrieval of memory,[17] to cerebral morphological changes, to psychiatric comorbidity and/or to the use of AEDs. We found that female gender was a risk factor for cognitive problems, even after controlling for increased psychiatric comorbidity. Polytherapy and not being seizure free indicates refractory epilepsy. We were surprised to find that in our cohort of PWE, memory

problems were more often reported among those in a relationship than in those who stated that they were not in a relationship. One explanation could be that memory problems are more evident and noticeable if a person is in a relationship.

Cognitive and affective problems often overlap. Cognitive problems might be related to the epilepsy itself and its underlying aetiology, to AEDs, to psychiatric comorbidity or to a combination of these factors. For some patients, such problems may have a greater impact on their quality of life than the seizure themselves.[18,19] Several studies have shown that cognitive problems occur frequently (70%-80%) in PWE,[20] with recurring tonic-clonic seizures particularly associated with a decline in cognitive function.[20]

4.2 | Medical problems

In a review and meta-analysis on fatigue (extreme and persistent tiredness) in epilepsy, Kwon and co-workers found fatigue occurred in up to 50% of the patients.[21] In seven of the studies included in the meta-analysis, a significant correlation was found between depression and fatigue. In one study, seizure frequency was an associated risk factor.[21] In contrast with the results of our study, gender and number of AEDs being in use were not risk factors in that study.[21] However, we asked about tiredness, which is a less specific term than fatigue.

Results from studies on headache in the epilepsy population are contradictory.[22] In our study, there was a high prevalence of reported headache, particularly in those who were not seizure free.

4.3 | Psychosocial problems

A recent meta-analysis on depression in epilepsy, including 35 studies, reported a point prevalence of depression of 21.9%, with a higher occurrence of depression in females than males (26.4% vs 16.7%), as found in our study.[23] However, the studies are not entirely comparable, as the meta-analysis was based on studies of difficult-to-treat patients. Furthermore, in our study we asked the patients whether they felt depressed or down/blue and did not use a more objective evaluation of depressive symptoms.[24] It is likely that many of the patients reporting feeling depressed in our survey do not have clinical depression, and this probably explains the high occurrence (nearly 60%) in our sample.

Feeling depressed was also a risk factor for sexual problems, which were reported by 30% of the participants. This is a lower proportion than found in a previous study among drug-resistant patients with epilepsy (63%-75%).[25] As well as feeling depressed being associated with sexual problems, other significant associations with sexual problems were being above the mean age of the cohort, having a known epilepsy aetiology and being in a relationship. Both older age and feeling depressed are known to be associated with sexual problems in PWE.[26,27] As being in a relationship may provide patients with more opportunities for sexual activity, this may mean that any sexual problems are recognized more readily than in those living alone. In a study by Fisher et al,[6] 32% of the patients reported living with a constant fear of the next seizure; this is a lower proportion than in our sample (nearly 50%). Perhaps surprisingly, being seizure free did not reduce the fear of having a seizure. Feeling depressed could increase this fear, and female gender was also associated. Interestingly, Gaus et al[28] found a higher rate of seizure worry (afraid to have a seizure next month) in men (55%) vs women (40%) with epilepsy, while depressive symptoms were increased in women. The association to female gender which we found in our study with regard to feeling depressed and fear of being alone or fear of having a seizure is probably explained by the large overlap between depression and anxiety and the higher rate of affective psychiatric comorbidity among women.[29]

About one-third of our sample reported difficulties with social interactions. As we did not ask the patients to specify the difficulties, we may only speculate about the reasons. In a recent review by Steiger and Jokeit,[30] the authors emphasize that although social contacts have a positive effect on health, morbidity, and self-esteem and may counteract stress, PWE are also at a risk of reduced social cognitive skills and therefore may be more likely to experience communication and interpersonal difficulties. Overall, comorbid depression can be a strong barrier against many aspects of successful integration in society.[31]

Many studies have shown a higher rate of anxiety in the epilepsy population than in the general population.[32,33] Fear of being alone may be more related to feelings of depression, rather than anxiety as a defined clinical diagnosis. Studies about loneliness in epilepsy are rare. Fisher et al[6] found that 24% of PWE reported social stigma, fear of other people's reactions and feelings of shame and loneliness. Surprisingly, in our study feelings of loneliness were more often reported by younger PWE. This may partly reflect their unfulfilled expectations, also promoted via social media, that younger people are sociable, interactive and have a large social network.

4.4 | Physical limitations

In our study, around 40%-50% of the participants reported problems with physical activity. Two large population-based studies found that PWE had a similar level of physical activity as a reference population.[35,36] However, other studies have shown that PWE tend to be less physically active and have a poorer level of physical fitness than controls.[37,38] Fear of seizures is reported to be a risk factor for physical inactivity.[39] Driving regulations mean that not being seizure free is an obvious reason for transport problems among PWE.

4.5 | Limitations of the study

The percentage 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. Even if our study is comparable to previous studies with a similar proportion of seizure-free patients,[6] a selection bias may nevertheless have had an impact on our results. It is reasonable to assume that patients with active epilepsy have a higher degree of challenges and entailed an overestimation of problems.

Further limitations are the lack of a reference population answering the same questionnaire, the known problems with the validity of questionnaires comprised of close-ended questions, and a potential selection bias towards persons with a greater need for information than the "average" PWE. During the study period, nearly 50 000 unique users visited the website of the Epilepsy Association. This is about 1% of Norway's population. An explanation may be that during this period, when searching for epilepsy on the Norwegian Google site, the homepage of the Epilepsy Association was the first to pop up. However, only 1182 PWE chose to participate in the study. We have no information about the PWE who chose not to participate, while interest in participating in the study and answering the questionnaire might reflect that the participant perceives that they have considerable challenges in everyday life.

5 | CONCLUSIONS

The results of this study, reflecting a self-selected Norwegian population, provide insights into an important and probably underestimated component of epileptology, namely the everyday challenges that are faced by PWE and are not directly related to seizures. We found that even seizure-free patients struggle with considerable psychosocial, cognitive and physical problems. Such challenges add to the burden of epilepsy and addressing these challenges and identifying coping strategies and ways of mitigating the challenges should be a natural part of a comprehensive epilepsy care.

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CONFLICT OF INTEREST

Oliver Henning has received speaker's honoraria from Eisai, UCB and Livanova. Cecilie Johannessen Landmark has received speaker's honoraria from Eisai and GW Pharma. Morten Ingvar Lossius has been giving talks and participated in expert panels for Eisai and UCB. Karl Otto Nakken has no conflict of interest to disclose.

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