



People with epilepsy and their relatives want more information about risks of injuries and premature death

Oliver Henning*, Karl O. Nakken, Morten I. Lossius

National Centre for Epilepsy, Division of Clinical Neuroscience, Oslo University Hospital, Norway

ARTICLE INFO

Article history:

Received 5 February 2018

Revised 23 February 2018

Accepted 23 February 2018

Available online xxxx

Keywords:

Epilepsy

Death

SUDEP

Injury

Information

ABSTRACT

For most people with chronic diseases such as epilepsy, thorough knowledge of the disease is important in order to reduce feelings of insecurity and to enable better management of everyday life. Whether and when to inform patients and their families about all the risks associated with epilepsy is a matter of controversy.

Using a web-based survey, patients with epilepsy (PWE) ($n = 1183$) and carers, family members, or guardians of PWE, who could either answer on behalf of the patients (CBP) ($n = 676$) or on their own behalf (CAR) ($n = 231$) were asked whether they wanted information about the risk of epilepsy-related injuries and premature death and also whether they had received such information.

Ninety percent or more of PWE, CBP, and CAR reported that they wanted such information, and 50% of CAR, 81% of CBP, and 70% of PWE had received some information about seizure-related injuries. Regarding risk of unexpected death, 31% of PWE, 35% of CBP, and 28% of CAR had received information on this issue. Those with tonic-clonic seizures were most eager to obtain information on these matters, and those best informed about epilepsy-related risks were males and the youngest part of the cohort. The wish for more information or the likelihood of having already received information was independent of the individual's seizure situation.

This study demonstrates that there is a considerable gap between what the patients want regarding information and what they are actually given by healthcare providers.

© 2018 Elsevier Inc. All rights reserved.

1. Introduction

Although sudden unexpected death in epilepsy (SUDEP) is a rare complication, it is a source of considerable worry [1]. Although some studies indicate that the large majority of patients want to be informed about SUDEP [2–6], it is still a matter of controversy whether and when to inform patients and their families about all the risks associated with epilepsy [7]. Guidelines often recommend providing such information, and most experts would agree with this [1,8]. Nevertheless, the reality seems to be otherwise. According to Morton and coworkers [9], neurologists are reluctant to inform their patients about these issues, as 68.5% of them discussed SUDEP with only a few or none of their patients [9]. A survey among Italian pediatricians treating children with epilepsy revealed that 16.2% stated that all patients should be informed about the risk of SUDEP, but only 1.8% actually did so [10].

The purpose of this study was to assess the extent to which patients with epilepsy (PWE) and their family members (or carers or guardians)

wanted information about epilepsy-related risks and whether this need was met by healthcare professionals.

2. Material and methods

The study was a collaboration with the Norwegian Epilepsy Association (NEA) (i.e., the Norwegian branch of the International Bureau for Epilepsy (IBE); lay people). Between April 1st 2017 and September 5th 2017, an online questionnaire was available on the homepage of NEA, popping up for all those who visited the page. Visitors to the page were asked to complete a questionnaire regarding risk of epilepsy-related injuries and premature death. Information about the survey was also available via Facebook. The home page of the NEA is, while not an official information from the Norwegian health services, still an important source of information visited by approximately 100,000 users per year. At the time of the survey, the page did not contain specific information about injuries or SUDEP.

Participants could register as 1) PWE or carers, family members or carers, or guardians of PWE, who could either 2) answer on behalf of the patients (CBP), or 3) on their own behalf (CAR). Each participant could complete the questionnaire only once. Questions included background information and covered the patient's epilepsy, treatment,

* Corresponding author at: National Centre for Epilepsy, Division of Clinical Neuroscience, Oslo University Hospital, P.O. Box 4950, Nydalen, 0424 Oslo, Norway.
E-mail address: oliver.henning@ous-hf.no (O. Henning).

and follow-up, the information that had been received about the risk of seizure-related injuries or death, and whether they wanted such information. The options regarding information were “do not want information”, “have not received information”, “received information but wanted more”, “received good information”, and “do not remember”.

We assumed that PWE, CBP, or CAR who selected any option other than “do not want information” wanted such information. Those selecting “do not remember” or “do not want information” were excluded when calculating the percentage of PWE, CBP, or CAR who had or had not received information.

To investigate possible group differences, chi-square tests were performed. All reported p-values are 2-sided. Odds ratios (ORs) for factors indicating the wish to obtain more information or for having been informed about the increased risk of injury and premature death were estimated using bivariate and multivariate logistic regression analysis. Variables tested were gender, cohabitation or not, above or below the mean age of the participants, known epilepsy etiology, having tonic-clonic seizures, and having been seizure-free for 12 months or more. The study was evaluated by the regional ethics committee (ref. no.: 2017/563).

3. Results

In the study period, the NEA web site had 48,249 hits, and 2090 persons agreed to take part in the survey. Of these, 1183 (56.6%) were PWE, 676 (32.3%) were CBP who answered on behalf of someone with epilepsy, and 231 (11.1%) were CAR (family members, guardians, or carers answering for themselves). Demographic and clinical characteristics of the participants are summarized in Table 1, and results from the questions regarding information about seizure-related risks are presented in Table 2.

Of all PWE, CBP, and CAR participants, at least 90% wanted information about epilepsy-related risks like injuries (Fig. 1) or death (Fig. 2). Among those wanting information with regard to the risk of seizure-related injuries, 70% of PWE, 81% of CBP, and 50% of CAR had obtained at least some information, and 47%, 55%, and 24%, respectively, reported that the information that they had received on this topic was good. Among those wanting information regarding risk of seizure-related death, 31% of PWE, 35% of CBP, and 28% of CAR had received at least some information (Fig. 2), and 16%, 17%, and 11%, respectively, reported having received good information on this issue (Fig. 2).

Having tonic-clonic seizures was the only independent factor in a multivariate logistic regression analysis associated with wanting information about the risk of death (OR: 2.22; confidence interval (CI): 1.57–3.12; $p < 0.001$). Other factors did not reach statistical significance (data not shown).

Male gender (OR: 1.28; CI: 1.02–1.60; $p = 0.033$), having epilepsy of known etiology (OR: 1.27; CI: 1.01–1.58; $p = 0.040$), and being younger than the mean age of participants (OR: 1.31; CI: 1.04–1.64; $p = 0.019$) were all significant independent factors in a multivariate logistic regression analysis for having obtained information about the risk of epilepsy-related death.

Having tonic-clonic seizures (OR: 4.10; CI: 2.72–6.17; $p < 0.001$), living together with others (OR: 2.12; CI: 1.20–3.77; $p = 0.010$), and being younger than the mean age of participants (OR: 1.62; CI: 1.10–2.40; $p = 0.016$) were all significant independent factors for wanting information about the risk of epilepsy-related injuries.

Male gender (OR: 1.48; CI: 1.15–1.89; $p = 0.002$), having tonic-clonic seizures (OR: 1.44; CI: 1.13–1.84; $p = 0.004$), living together with others (OR: 1.58; CI: 1.20–2.08; $p < 0.001$), and being younger than the mean age of participants (OR: 1.52; CI: 1.19–1.94; $p < 0.001$) were all significant independent factors for having been provided with information about the risk of epilepsy-related injuries.

The wish for more information or having been informed about either risk was independent of being seizure-free or not or having consultations

Table 1

Demographic and clinical characteristics of the participants in the survey ($n = 1859$).

Characteristics	Patients (1183)	Carers answering on behalf of the patients (676)
Population (n)		
Age in years (yrs) (mean; range)	41.76 (2–93) ^a	16.23 (0–79) ^k
Male gender (%)	373 (32.4) ^b	350 (52.9) ^{l,**}
Living alone (%)	365 (31.8) ^c	42 (6.4) ^{m,**}
Under 18 years of age (n; %)	28 (2.4) ^d	437 (66.7) ^{k,**}
Age at first seizure (yrs) (mean; range)	20.99 (1–80) ^e	7.39 (0–78) ⁿ
Number of years with epilepsy (mean; range)	20.40 (0–72) ^f	9.09 (0–69) ^o
Seizure types, n (%)		
• Focal, not impaired consciousness	347 (29.4) ^g	210 (31.5) ^p
• Focal, impaired consciousness	425 (36.0) ^g	306 (45.9) ^p
• Tonic-clonic	720 (61.0) ^g	410 (61.6) ^p
• Absences	263 (22.3) ^g	275 (41.3) ^p
• PNES ^a	55 (4.7) ^g	22 (3.3) ^p
• Other	86 (7.3) ^g	112 (16.8) ^p
• Don't know	108 (9.1) ^g	31 (4.7) ^p
Seizure-free last year, n (%)	480 (40.7) ^h	151 (22.7) ^{k,**}
Epilepsy etiology, n (%)		
• Known	544 (46.3) ⁱ	260 (39) ^{q,*}
• Unknown	631 (53.7) ⁱ	407 (61) ^q
Follow-up at n (%)		
• Neurologist (child or adult)	804 (68.1) ^g	554 (83.3) ^k
• Epilepsy nurse	150 (12.7) ^g	115 (17.3) ^k
• General practitioner	393 (33.3) ^g	125 (18.8) ^k
• No regular follow-up	224 (19.0) ^g	64 (9.6) ^k
Frequency of follow-up		
• Less than once per year	143 (16.8) ^j	26 (4.5) ^r
• Once per year	371 (43.6) ^j	175 (30.4) ^r
• 2–4 times per year	297 (34.9) ^j	300 (52.1) ^r
• More than 4 times per year	40 (4.7) ^j	75 (13) ^r

PNES = psychogenic nonepileptic seizures.

** $p < 0.001$.

* $p < 0.01$.

^a 1157/1183 answered.

^b 1115/1183 answered.

^c 1151/1183 answered.

^d 1157/1183 answered.

^e 1153/1183 answered.

^f 1130/1183 answered.

^g 1181/1183 answered.

^h 1180/1183 answered.

ⁱ 1175/1183 answered.

^j 851/1183 answered.

^k 655/676 answered.

^l 662/676 answered.

^m 661/676 answered.

ⁿ 644/676 answered.

^o 634/676 answered.

^p 666/676 answered.

^q 667/676 answered.

^r 576/676 answered.

with a neurologist or an epilepsy nurse at least once per year (data not shown).

3.1. Discussion

Epilepsy may have many unfortunate consequences. Among these are seizure-related accidents and, at worst, premature death. To reduce the risk of such unfavorable incidents, it is important to discuss these matters with the patients and the relatives to empower them to take responsibility themselves for the condition, e.g., to avoid seizure triggers. To assume that they are well informed about the risks associated with epilepsy could be precarious.

In Norway, most PWE (about 2/3 in our cohort) are followed up by neurologists (child and adult) while the remainder is followed up by general practitioners (GPs). Nevertheless, our survey demonstrated that only one-third of the study cohort had been provided with information about epilepsy-related risk of death. The term SUDEP was deliberately not used

Download English Version:

<https://daneshyari.com/en/article/8683640>

Download Persian Version:

<https://daneshyari.com/article/8683640>

[Daneshyari.com](https://daneshyari.com)