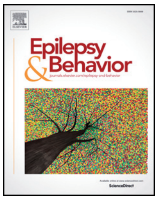
Epilepsy & Behavior xxx (2017) xxx–xxx

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh



Knowledge of sudden unexpected death in epilepsy (SUDEP) among 372 patients attending a German tertiary epilepsy center

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ARTICLE INFO

Article history:
Received 16 September 2017
Revised 28 November 2017
Accepted 29 November 2017
Available online xxxx

Keywords:
SUDEP
Sudden unexpected death in epilepsy
Education
Survey

ABSTRACT

Background: There is evidence that the sudden unexpected death in epilepsy (SUDEP) risk can be reduced by good seizure control, nocturnal supervision, and by early cardiopulmonary resuscitation if cardiorespiratory arrest occurs in the aftermaths of generalized tonic–clonic seizures (GTCS). These measures, however, may critically depend on the knowledge of patients and relatives on SUDEP. Here, we assessed the basic knowledge on SUDEP of people with epilepsy at a tertiary epilepsy center in Germany.
Methods: Adult patients with epilepsy and relatives or caregivers of patients with epilepsy aged 16 years or older attending our outpatient clinic from January to March 2014 were given the opportunity to participate in a (assisted or unassisted) written survey. In the anonymized questionnaire, people were asked if they had already heard about SUDEP, by what means and if they wish to learn (more) about SUDEP. Furthermore, age, sex, epilepsy duration, highest degree of education, number of GTCS during the last year, and estimation of subjective impairment by their disease were assessed. Statistics were done using mixed linear or logistic regression models.
Results: A total of 372 patients' questionnaires were included in this survey. More than 87% of the participants had never heard of SUDEP before. Whereas about 50% of the participants wanted to learn more about SUDEP, about 40% did not. Only the age at survey was significantly associated with both being informed and the desire of learning more about SUDEP: Younger patients had more often heard ($p = 0.022$) and wanted to know more about SUDEP ($p = 0.020$). Thirty-nine patients were considered at high risk for SUDEP. Of these, only 6 patients (15%) knew about SUDEP prior to this survey, but 18 patients (46%) wanted to learn more about this fatal complication.
Conclusion: Our data suggest that the level of information on SUDEP among people with epilepsy is poor in Germany regardless of sex, school education, or epilepsy severity. Additionally, a considerable proportion of people with epilepsy seems to prefer not getting detailed information on SUDEP. More efforts are required to understand the potential barriers of the education of patients and relatives on sudden death with the ultimate goal of decreasing the risk of SUDEP.

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1. Introduction

Sudden unexpected death in epilepsy (SUDEP) is the most frequent directly epilepsy-related cause of premature death in people with epilepsy [1]. Its incidence rates are age-dependent and amount to 0.22 per 1000 patient years in children with epilepsy and 1.2 per 1000 patient years in adults [2]. According to epidemiological estimations, SUDEP alone causes about 100.000 years of potential life lost in the U.S. each year, ranking second only to stroke when selected neurological diseases as cause of death are considered, highlighting its public health burden [3].

Sudden unexpected death in epilepsy is likely to be a fatal complication of generalized tonic–clonic seizures (GTCS) in most cases [4,5]. Therefore, it is not surprising that improved or full seizure control appears to reduce the SUDEP risk, e.g., by efficacious adjunctive antiseizure treatment or successful epilepsy surgery [6,7]. Furthermore, nocturnal supervision of people with epilepsy, whether by the presence of a person in the patient's bedroom or by using acoustic devices, seems to lower the SUDEP risk [8]. The latter observation may be related to the lethal cascade ultimately leading to SUDEP, involving postictal suppression of brain stem functions, central apnoea, and secondary terminal asystole in the aftermaths of GTCS [5]. In these instances, early cardiopulmonary resuscitation appears to prevent SUDEP [5], but may not be successful in every case [9].

Altogether, there is plausible evidence that the SUDEP risk can be actively reduced by modifying antiseizure treatment and by taking

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https://doi.org/10.1016/j.yebeh.2017.11.036
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Please cite this article as: Surges R, et al, Knowledge of sudden unexpected death in epilepsy (SUDEP) among 372 patients attending a German tertiary epilepsy center, Epilepsy Behav (2017), https://doi.org/10.1016/j.yebeh.2017.11.036

other measures [5–8,10]. The active management of the SUDEP risk, however, requires good knowledge about SUDEP and its risk factors. Therefore, the National Institute for Health and Care Excellence (NICE), the Scottish Intercollegiate Guidelines Network, and the American Epilepsy Society advocate discussion of SUDEP with patients and families early in the clinical course of the disease which may allow patients, relatives, and caretakers to change behavior or take preventive measures [2,11,12]. Previous surveys in Germany, Italy, the UK, and the U.S. investigated whether physicians discuss SUDEP with patients or relatives. The proportion of physicians discussing SUDEP with all or most of their patients or parents varied between 12 and 30% [13–16], suggesting that cultural differences may play a role in attitudes toward counseling about SUDEP. This is mirrored by a considerable lack of knowledge of SUDEP in patients with epilepsy or their families [17–20]. Here, we assessed the knowledge of SUDEP among patients attending a tertiary epilepsy center in Germany and ascertained to explore influencing factors with the ultimate goal to identify needs and strategies to improve education of patients, relatives, and caregivers.

2. Patients and methods

2.1. Patients

Adult patients with epilepsy aged 18 years or over as well as adult relatives or caregivers of patients aged 16 years or older attending our outpatient clinic from January to March 2014 were asked to participate in an anonymized written survey. In many cases, the filling out was assisted by the treating physician who complemented data on patient history in the presence of the participant. All patients, relatives, or caretakers were given the opportunity to ask further questions and to attend a meeting of the local support group of people with epilepsy with in-depths information on comorbidities, mortality, and SUDEP. The anonymized paper survey was waived from ethic approval by the local medical ethical committee at the Medical Faculty of the Rheinische Friedrich Wilhelms University of Bonn.

2.2. Questionnaire

People were asked if they had already heard about SUDEP (a short explanation was given: SUDEP is the very rare sudden unexpected death of people with epilepsy) (possible answers: yes, no), by what means (possible answers: treating physician, internet, print media, or other sources), and if they wish to learn (more) about SUDEP (possible answers: yes, no, unsure). Furthermore, age (age groups: ≤18 years, 19–29, 30–39, 40–49, 50–59, or ≥60), sex, epilepsy duration (duration groups: <1 year, 1–5 years, 6–15 years, or >15 years), estimation of subjective impairment by epilepsy itself (graded between 1 and 6 being 6 the highest grade of impairment), the estimated number of GTCS during the last 12 months, and highest degree of education (in total years: none, 9 years, 10 years, 12–13 years, or others) were assessed. The number of education years typically equals the following levels: 9 years equals the basic school education (in Germany “Hauptschul- or Volksschulabschluss”), 10 years equals the secondary school level I certificate (in Germany “mittlere Reife”), and 12 to 13 years equals the general qualification for university entrance or vocational diploma (the so-called “Abitur” or “Fachabitur”).

2.3. Statistical analysis

Statistics were done using mixed linear or logistic regression models with the help of STATA12 software (StataCorp LP, TX, U.S.A.). Information on lacking data is given where necessary. p-Values < 0.05 were regarded as statistically significant.

3. Results

A total of 372 participants' questionnaires were included in this study. Hundred and ninety-five participants (52.4%) were of male and 175 of female sex (information was not provided in 2 patients), 208 (56.1%) patients were between 16 and 39 years (information was not provided in 2 patients). Epilepsy duration amounted to more than 15 years in 192 (51.6%) patients (information was not provided in 5 patients). Twenty-nine (7.8%) patients had no regular school education, 23 (6.2%) patients attended a special school for people with mental or physical handicap, 207 (56.4%) patients had a basic school education (9–10 years), 98 (26.3%) patients had accomplished the general qualification for university entrance or vocational diploma, and 10 (2.7%) patients had attended university (information was not provided in 5 patients). About 60% of the patients felt not or only moderately impaired by their disease, whereas only about 2% felt severely restrained (information was not provided in 8 patients). Further details are illustrated in Fig. 1.

Generalized tonic–clonic seizures occurred in 135 patients with an estimated total number of 15 ± 39 GTCS (mean ± SD) during the last 12 months prior to the survey. Two hundred and twenty-five (60.5%) patients reported no GTCS during the last 12 months prior to this survey (information was not provided in 12 patients). Forty-six (12.4%) patients had already heard of SUDEP prior to this survey, whereas 326 patients had never heard of SUDEP before (Fig. 2A). The informed patients had mostly taken the knowledge of SUDEP from the internet or print media, only 4 patients were told by their treating physician (Fig. 2A inset) (information was not provided in 8 of 46 patients). Importantly, 188 (50.5%) of the patients wanted to learn more about SUDEP, whereas 151 (40.6%) patients did not, 31 (8.3%) patients were unsure (Fig. 2B) (information was not provided in 2 of 372 patients).

Only the age at survey was significantly associated with both the information and the desire of getting more information on SUDEP (Table 1). Younger patients had more often heard about SUDEP ($p = 0.022$) and wanted to learn more about SUDEP ($p = 0.020$) as compared with older patients. For instance, in the patient group up to the age of 40 years, 70 (34%) have not heard about SUDEP, 120 patients (58%) knew about SUDEP, and 18 patients (8%) were not sure whether they had heard about SUDEP. In contrast, in the patients older than 40 years, only 68 patients (41%) knew about SUDEP, whereas 81 patients (50%) have not heard about SUDEP (14 patients were not sure). Thirty-nine patients were considered at high risk for SUDEP (epilepsy duration >15 years, GTCS during the last 12 months, male sex). Of these, only 6 (15%) have heard from SUDEP prior to the survey, but 18 patients (46%) wanted to learn more about this fatal complication.

4. Discussion

We found that the level of information about SUDEP was poor among people with epilepsy or their caregivers attending a German tertiary epilepsy center, which appears to be a rather consistent finding across surveys in other countries with a proportion of informed patients between 14 and 34% [17–20]. In our population, the only factor that appeared to have an impact on whether people knew about SUDEP was the age: younger patients were more likely to be informed about SUDEP, but there was no association with the number of GTCS or duration of epilepsy as recently reported by a survey at an epilepsy center in North America [18]. Xu and coworkers have not found any association between patient characteristics and awareness of SUDEP in an Australian survey [19]. Maybe the most surprising and alarming finding of our survey was the relatively high proportion of participants who did not want to get *more information* on SUDEP. Although the participants were given the opportunity to talk with the treating physician or to attend a meeting of the local support group of people with epilepsy, about 40% of the respondents did not want to learn *more* about SUDEP. Our observation replicates the finding of a previous survey in which only about 60% of

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