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The lived experience of initial symptoms of and factors triggering epileptic seizures

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ABSTRACT

The aim of this study was to document the self-perception of initial symptoms of and factors triggering epileptic seizures in a sample of people with epilepsy (PWE) and their carers. Among 600 participants, questionnaires were returned by 309 (51.5%), of whom 72.8% were PWE and 27.2% were carers and others. Experiencing at least one symptom prior to a seizure was reported by 86.9% of PWE and 74% of carers. The most common symptoms were a funny feeling, confusion, and anxiety. Experiencing one trigger that resulted in a seizure was reported by 89.8% of PWE and 85.5% of carers. The most common triggers were tiredness, stress, and sleep deprivation. Among PWE and their carers, 63.6% and 51.3%, respectively, indicated that they can tell when a seizure is about to occur, and 26.7% and 15.4%, respectively, indicated that they felt they could stop a seizure. The most common techniques were resting, medication, and relaxation.

1. Introduction

Epilepsy is a neurological disorder characterized by unpredictable, recurring episodes known as seizures. It encompasses a number of seizure types, and characteristic conditions that are not only important diagnostically, but also appear to influence the subjective experience of having epilepsy. Warning signs and initial symptoms of epilepsy have been recognized for centuries [1]. By the early 20th century, protective activities such as monitoring hydration levels, dietary ketosis, and controlling excessive emotional stress and fatigue were advocated as therapeutic measures, although these methods were largely forgotten as improvements in antiepileptic drugs and brain monitoring (e.g., EEG) continued [2]. The recognition that antiepileptic medication and surgery does not work for many people with epilepsy (PWE) has renewed interest in the use of other therapeutic methods [3]. More recently, Haut et al. [4] found that patients can identify periods of increased risk of seizure. Warning signs that precede a seizure are called premonitory symptoms, and can occur from 10 min to several days in advance. Of the few studies published on premonitory symptoms, the findings indicate that between 7% and 50% of the population with epilepsy may experience at least one symptom [5–7]. Simple partial seizures (including auras) can also be considered a warning sign for many people who also experience other types of seizures [6].

Precipitants can be defined as “those circumstances that precede the onset of an epileptic attack and are considered by both patient and neurologist to be a possible explanation for why the seizure happened when it did” [3]. According to Aird and Gordon [2], seizure precipitants include both seizure-inducing, for example, environmental or endogenous origin, and seizure-triggering, for example, chemical or physiological stimulation factors. A well-known phenomenon is seizures that are triggered by flashing lights. As epilepsy is a group of heterogeneous disorders, each with a different physiology, seizure precipitants can vary widely among individuals [8].

Epilepsy is a widely researched medical condition; however, the research on subjective experiences of seizure precipitants is relatively uncommon, with only a small number of studies published over the past 20 years. Of those studies that have investigated seizure precipitants, the percentages of PWE experiencing at least one type ranges from 29% ($N = 148$, Hughes et al. [5]) to 92% ($N = 75$, Da Silva Sousa et al. [9]). Studies have been done around the world and with samples of patients with epilepsy with different seizure types and conditions, yet all of the studies demonstrate that many people experience seizure precipitants. The most common seizure precipitant across studies is “stress.” Other precipitants also rated highly include sleep deprivation, fever, tiredness, menstruation, and missed medication.

Despite the evidence that people experience initial symptoms and triggers of epileptic seizures, the extent to which seizures are predictable (and thus controllable) is contentious. As Millet et al. [10] argue, most PWE experience random seizures, and anecdotal reports of associations between seizures and certain activities such as cognitive exertion are the result of people wanting to attribute a cause to seizures. Millet et al. failed to find an association between cognitive exertion (a commonly mentioned seizure precipitant) and increased risk of seizures, and concluded that peo-

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ple may be unnecessarily restricting their lifestyles and missing many opportunities for fear of having a seizure. Conversely, Rajna et al. [11] put forward a medical hypothesis that for people with weak epileptic susceptibility, the occurrence of an epileptic seizure requires a very strong precipitating/provoking event, which means such a case is best managed by eliminating the event rather than taking antiepileptic drugs. Indeed, Aird [12] achieved good results by promoting moderate lifestyle changes, with results that were comparable to those of treatment with most of the new antiepileptic drugs. However, Rajna et al. [11] did concede that the subjective nature of precipitating events is difficult to prove scientifically and that there is extreme interindividual variability.

As technology has improved, more research has been conducted using EEGs to measure changes in the period before the onset of a seizure, although there is not a clearly accepted nomenclature for relevant periods for seizure prediction [13]. Hughes [14] reviewed a number of studies testing seizure prediction by monitoring EEGs and analyzing outcomes using nonlinear methods, and found that only 21% of studies could be specific about the time at which to predict a seizure episode (median value: 6–7 min). Hughes also found that 16% of studies reported negative or nonspecific findings, and highlighted the difficulties associated with using complex methods requiring high-level mathematical expertise to test objective seizure prediction.

The highly idiosyncratic nature of seizure precipitants also creates difficulties in applying feasible therapeutic alternatives based on EEG findings. Subjective experiences may be more useful in assisting health professionals to devise treatment plans tailored to the individual, and therefore improvements in awareness and understanding could encourage people to learn how to recognize initial symptoms and triggers of their seizures. Understanding the processes associated with their seizures may lead persons with epilepsy to feel like they have some control over their condition.

The specific objectives of this study were to examine the self-perception of initial symptoms and triggers of epileptic seizures in a sample of PWE; to investigate the perceived self-control in managing epileptic seizures and the techniques used; and to explore differences in demographic characteristics, living with epilepsy characteristics, and seizure types in relation to seizure prediction and self-control for PWE.

2. Methods

Participants were recruited from the Epilepsy Foundation of Victoria's social research participant register. Researchers at the Epilepsy Foundation of Victoria have established a database of people interested in participating in epilepsy research. The survey was constructed by combining a number of different elements of the existing literature to produce the Seizure Prediction Tool (SPT). The SPT contained three sections: demographic details, living with epilepsy, and premonitory symptoms and triggers.

Following ethics approval from Monash University's ethics committee, the people registered on the Epilepsy Foundation of Victoria social research database were sent a package through the mail containing an introductory letter encouraging people to participate and return the survey as soon as they could, the plain language statement, the survey, and a reply paid envelope. Data were collected for approximately 2 months following the initial mailout, and were then summarized and analysed using SPSS. Following the descriptive methods, the data were analyzed for statistically significant associations between variables using χ^2 tests (Fisher's exact tests when applicable), *t* tests, and Mann–Whitney *U* or Kruskal–Wallis tests for assessing mean rank differences in ordinal variables. A significance level of 0.05 was used to assess statistical significance.

3. Results

3.1. Basic characteristics of the sample

Participants provided information on the following demographic characteristics: epilepsy status, age, gender, educational level, employment status, marital status, living situation, and living arrangements. Of the 309 participants, 225 (72.8%) were PWE, 78 (25.2%) were carers[1] of PWE, and 6 (1.9%) people were classified as "other" (e.g., friend, former carer). The mean age of the total sample was 48.4 years (SD = 15.7, min = 10, max = 89). There were significantly more female participants (68.9%) than male participants (31.1%): $\chi^2(1, N = 309) = 44.30$, $P < 0.05$. The most frequent categories for the remaining demographic characteristics for the total sample were Caucasian (93.5%) for ethnic background, high school certificate (37.5%) for educational level, retired (23.3%) for employment status, and married (48.9%) for marital status.

Of 309 participants, 299 reported the length of time they (or the person for whom they cared) have had epilepsy: $M = 22.6$ years, SD = 16.2, min = 0, max = 82. For PWE, the mean number of years they had epilepsy was 24.95 (SD = 16.7), compared with a mean of 16.8 years (SD = 13.5) reported by the carers of PWE, a difference that is statistically significant, $t(157.1) = 4.23$, $P < 0.05$. In terms of age at first seizure, 296 people responded: mean = 20.5 years, SD = 17.8, min = 0, max = 78. For PWE, the mean age of first seizure was 21.6 (SD = 17.3), compared with a mean of 17.00 years (SD = 18.3) reported by the carers of PWE, a difference that was also statistically significant, $t(289) = 1.99$, $P < 0.05$.

Respondents provided information on the types of seizures they experienced, choosing as many as applicable from a list of seven options: simple partial, complex partial, absence, tonic–clonic, myoclonic, tonic, and atonic seizures. Of the 309 participants, 32 (10.4%) failed to report any seizure type. Tonic–clonic seizures were the most common, with 56.9% of all respondents experiencing this type of seizure. Myoclonic, tonic, and atonic seizure types were rare for the current sample, with only 7.1%, 5.2%, and 3.9% of respondents experiencing these types of seizure, respectively. Of the remaining seizure types, 19.4% of respondents experienced simple partial seizures, 33.7% experienced complex partial seizures, and 35.9% experienced absence seizures.

3.2. Recognition of initial symptoms predicting seizures

Of 309 participants, 305 (98.7%) responded to the question "Have you experienced/noticed any of the following symptoms just before a seizure?" with the 16 possible symptoms and frequencies of responses listed in Table 1. Participants could choose as many as were appropriate for their circumstances. Only 29 (12.9%) PWE and 20 (25.6%) carers of PWE did not experience any symptoms, meaning that 86.9% of PWE and 74% of carers experienced at least one symptom prior to a seizure.

PWE and carers of PWE were compared with respect to their experience of the symptoms "a funny feeling," confusion, anxiety, and irritability symptoms. Statistical analysis revealed that only "a funny feeling" differed significantly with epilepsy status, with PWE reporting "a funny feeling" at a higher rate than expected (154 participants), and carers of PWE reporting this symptom at a rate lower than expected (33 participants): $\chi^2(1, N = 303) = 16.7$, $P < 0.05$.

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[1] A *carer* is someone who looks after the person with epilepsy. He or she can be a family member, a friend, or a community member.