

Subjective perception of seizure precipitants: results of a questionnaire study

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We evaluated self-perception of seizure precipitants in 149 adult subjects with epilepsy: 71% of the subjects reported at least one factor that, according to the perception, increased the risk of suffering from a seizure. The subjects most often reported psychological stress, change of weather and sleep deprivation. Among the disease-related factors, seizure frequency and the state of consciousness at the onset of the seizures influenced perception of precipitants. Furthermore the perception of some precipitants was dependent on such social variables as rural versus urban surroundings. It is argued that the perception of seizure precipitants is the result of a combination of physiologically based temporal and causal correlations and of beliefs of the patient about such relationships. Hence reports of seizure precipitants are determined by somatic as well as psychological factors. Efforts to clarify the relationship between possible precipitants and the occurrence of seizures should be intensified. In addition the great importance of seizure precipitants in lay theories of epilepsies should be considered in counselling patients with epilepsies.

Key words: epilepsy; triggers; awareness; psychosocial factors; stress; weather.

INTRODUCTION

Epilepsy is defined as a condition of recurrent spontaneous seizures not directly related to a specific triggering event. Reflex epilepsies, hence conditions where seizures are always or mostly followed by specific stimuli, are well known but represent only a small part of epileptic disorders. Nevertheless, it is widely accepted that the occurrence of seizures is not completely random, but is promoted or inhibited by external or internal stimuli. The dependency on circadian rhythms is acknowledged to be an essential feature in some syndromes as in epilepsy with grand mal seizures on awakening¹. The relationship to the endocrinological state that results in catamenial epilepsy has been discussed recently^{2,3}.

A great number of other possible relevant variables have been described⁴. Antebi and Bird^{5,6} have stressed the importance of psychological factors. In addition in our experience subjects often claim other factors like change of weather as being relevant to triggering their seizures. Interestingly data are sparse on these issues, though it would be important to rely on objective data when counselling patients. In particular, the com-

plicated interrelationship between psychological stress and the occurrence of seizures deserves more attention, as has recently been stressed by Betts⁷ and by Lai and Trimble⁸. One likely explanation for the rarity of studies about these issues is the methodological difficulty of proving a causal relationship between a potential trigger and a seizure and to rule out mere coincidence. The issue is complicated by the fact that a perceived connection between a potential precipitant and the event of a seizure not only depends on a causal relationship, but may also reflect the beliefs of the patient (or the doctor). The desire of the patient to gain control over the occurrence of seizures could, in turn, influence such beliefs. It has been demonstrated that the perception of loss of self-control is a frequent consequence to the experience of recurrent seizures⁹. Furthermore, humans are not very competent in discerning randomness from non-randomness¹⁰ and are prone to interpret connections as causal ones.

Within a larger questionnaire study on the psychosocial aspects of epilepsy we have explored potential seizure precipitants by asking patients about their perceptions of some possible triggering factors. We have then looked for correlations between these reports and

seizure-related and psychosocial factors, exploring the hypothesis that the perception of precipitants is a function of the seizure disorder itself and of psychological reactions to the experience of seizures.

METHODS AND MATERIALS

Methods

We developed a questionnaire that, following questions concerning the psychosocial aspects of epilepsy, included questions about perceived precipitants of seizures. The results of this part of the questionnaire are reported in this paper. We explicitly asked for six possible precipitants (sleep deprivation, alcohol, physical exercise, psychological stress, menses, and change of weather). In addition we asked the subject whether there are other precipitants whatever they might be. Furthermore we asked whether the subject thought that she or he is sometimes able to influence the course of a seizure.

Subjects

We distributed the questionnaires by handing them to neurologists and epilepsy clinics throughout Austria to be given to the subjects. The subjects were asked to fill in the questionnaire at home and mail it to us. The results presented in this study are from the first 151 questionnaires we have received from adult (at least 17 years old) patients (87 female, 64 male). The mean age was 35.9 years ($SD = 12.9$). Age at onset of epilepsy was 16.0 years ($SD = 14.8$), and duration of epilepsy was 19.9 years ($SD = 12.4$). Eighty subjects (57%) reported suffering from more than one seizure during the last month. Twenty-seven subjects (19%) reported that they had not suffered from any seizures during the last 12 months.

Some 47% of the subjects were working; 44% were living in towns with more than 20 000 inhabitants, while the others came from rural areas. Classification of seizures and syndromes is very unreliable if based on patients' reports only¹¹. Therefore we restricted ourselves to asking whether the subject's seizures are accompanied by an impairment of consciousness and whether the subject is unconscious at the onset of all of the seizures (hence whether the subject at least sometimes experiences an aura). In the replies 73% of the subjects reported that at least some of their seizures include loss of consciousness; 56% reported that they are at least sometimes aware of the beginning of a seizure.

RESULTS

Data management and statistical analysis were done using SPSS for Windows 6.0 software. Frequency tables were evaluated using the chi-squared test with Fisher's exact test when applicable. A p -value less than 0.05 was considered significant.

One hundred and eight subjects (72%) reported at least one precipitant. The most often given precipitant was psychological stress (52 subjects, 34%); the next frequent was change of weather (45 subjects, 30%). Thirty-six subjects (24%) reported that sleep deprivation increased the likelihood of their seizures; 13 subjects (9%) reported alcohol, 27 subjects (18%) physical exercise and 20 subjects (22% of the female subjects) menses. Sixteen subjects (11%) reported at least one other precipitant. Four subjects (3%) had experienced seizures triggered by photostimulation (television, stroboscope light in discotheques); two (1%) subjects saw a correlation between their seizure frequency and the lunar phase. Two (1%) subjects reported having more seizures when they are relaxed. Another two (1%) subjects reported suffering from seizures when frightened, hence from a startle epilepsy. One subject reported having seizures triggered by pain, one other by masturbation. Three (2%) gave medical problems or medication as precipitants for their seizures. Interestingly, often more than one precipitant factor was reported. Thirty subjects reported one precipitant; 19 subjects reported two, 19 subjects three, and two subjects four precipitants.

Figure 1 shows the percentage of subjects that reported the single precipitants separated for gender and for rural versus urban living surroundings. The only significant difference between female and male subjects was the precipitating effect of the intake of alcohol ($\chi^2 = 5.88$, $df = 1$, $p = 0.015$), presumably reflecting the higher percentage of alcohol-related seizure disorders in the male population. In contrast to common prejudices psychological stress was if at all more often reported by male subjects. Subjects living in rural surroundings reported significantly more often that their seizures were influenced by change of weather ($\chi^2 = 3.93$, $df = 1$, $p = 0.047$). There was a trend for catamenial epilepsy to be reported more often in this population that however failed to be significant ($\chi^2 = 1.20$, $df = 1$, $p = 0.27$). We found no differences in the answers between subjects who were working and those who were not. The same was true for the marital status.

Figure 2 shows the dependency of the perception of precipitants on seizure frequency and on whether a subject experiences auras. Subjects with frequent seizures reported significantly more often that the occurrence of their seizures is influenced by the weather ($\chi^2 = 7.88$, $df = 1$, $p = 0.005$), while the contrary was true

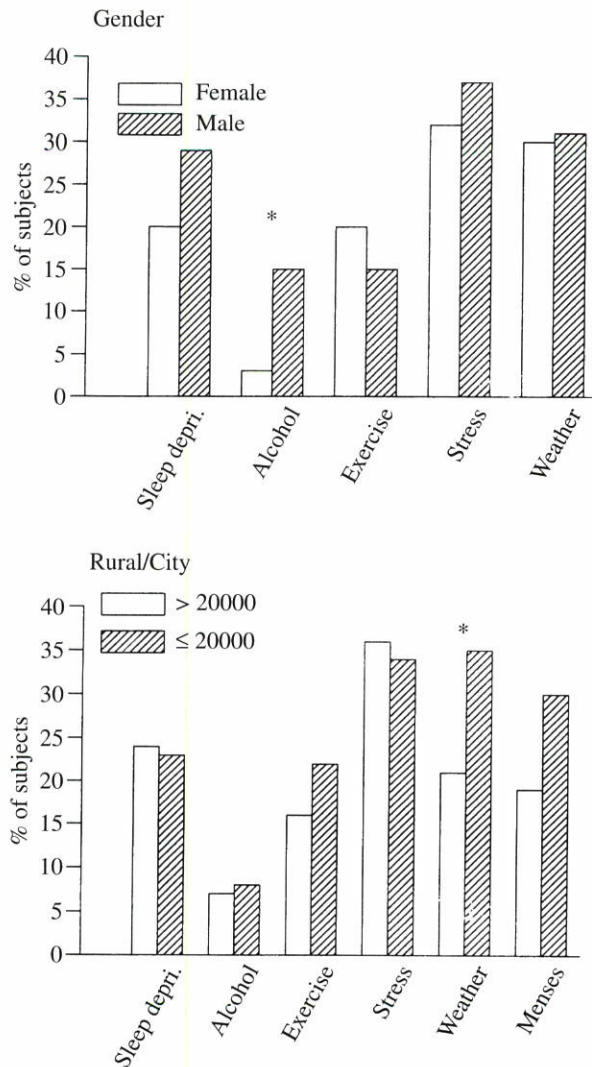


Fig. 1: Perception of seizure precipitants in dependence of gender respective of rural/urban surroundings, for menses $n = 87$, elsewhere $n = 151$; sleep depri., sleep deprivation; *, $p < 0.05$.

for alcohol ($\chi^2 = 5.38$, $df = 1$, $p = 0.02$). The trend for a greater percentage of (female) subjects with frequent seizures reporting catamenial epilepsy just failed to be significant ($\chi^2 = 3.38$, $df = 1$, $p = 0.07$). No single precipitant was reported significantly more often by subjects who regularly experience an aura. However, 85% of the subjects with auras reported at least one precipitant factor, but only 61% of the subjects who do not ($\chi^2 = 10.58$, $df = 1$, $p = 0.001$). There was no significant difference in any of the precipitants between subjects whose seizures are accompanied by loss of consciousness and whose are not.

Twenty-five subjects (17%) reported that they could at least sometimes influence the course of an ongoing seizure. Twenty-one (33%) of the subjects with auras, but only three (4%) of the subjects without auras, reported that they are able to do so ($\chi^2 = 23.1$, $df = 1$, $p < 0.01$). Subjects that reported being able

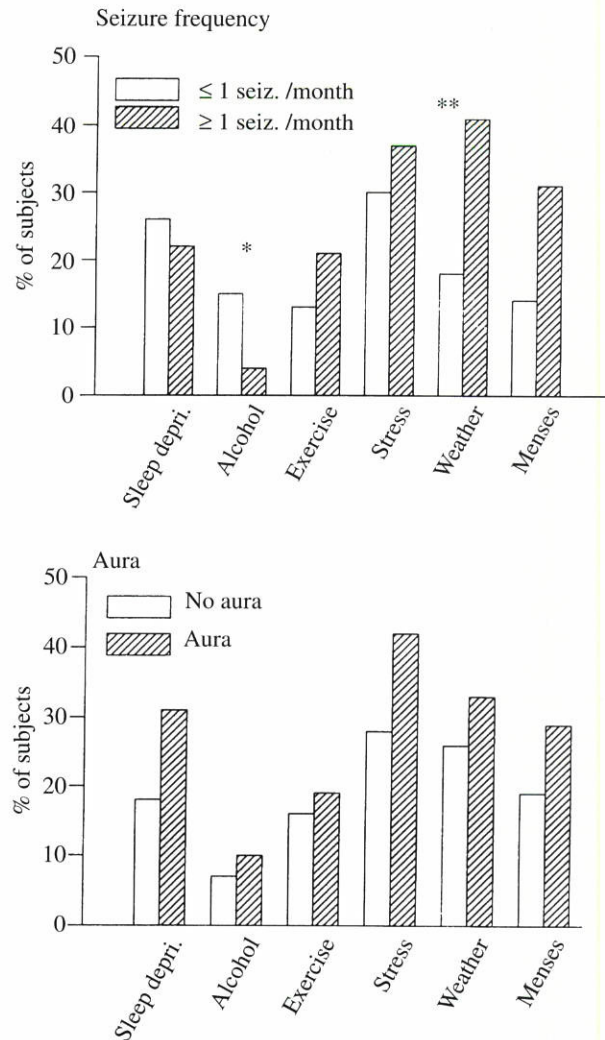


Fig. 2: Perception of seizure precipitants in dependence of seizure frequency respective aura, for menses $n = 87$, elsewhere $n = 151$; sleep depri., sleep deprivation; *, $p < 0.05$; **, $p < 0.01$.

to influence the course of their seizures did not differ significantly in any other psychosocial or disease-related measure from the other: 96% of the subjects that reported being able to influence the course of their seizures (vs. 68%, $\chi^2 = 8.33$, $df = 1$, $p < 0.01$) reported one or more external precipitants. Among the single factors, sleep deprivation and stress were significantly more often reported ($\chi^2 = 6.45$, $df = 1$, $p = 0.01$; respective $\chi^2 = 4.21$, $df = 1$, $p = 0.04$).

DISCUSSION

The first remarkable finding of our study is the high number of subjects reporting precipitating factors. This is in contrast to the definition of epilepsy as a condition of recurrent *unprovoked* seizures. However, this stands in line with previous reports. In one study¹² two-thirds

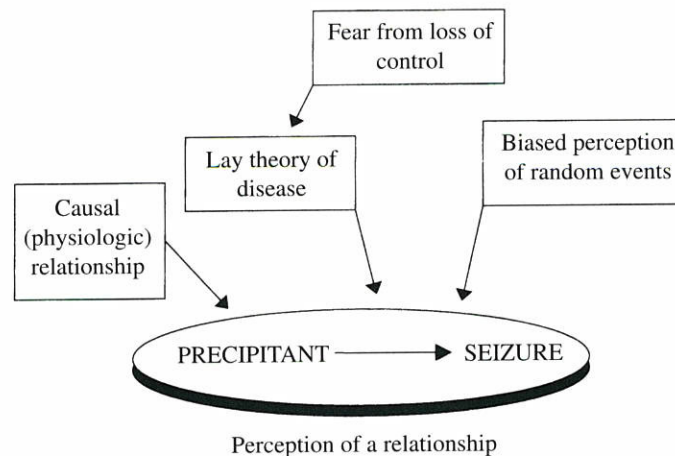


Fig. 3: Diagrammatic representation of potential sources of the perception of seizure precipitants.

of the subjects claimed that emotional stress triggers their seizures. The same number was reported by Antebi and Bird⁶ in their study on facilitatory factors. In contrast to these findings Neufeld and colleagues¹³ reported that only 8% of their patients had an increase in seizure frequency during missile combat, reasonably a situation of high-level psychological stress. Neugebauer and colleagues¹⁴ drew a similar conclusion. In one of the few prospective studies Tempkin and Davis¹⁵ could demonstrate an influence of daily stress levels on seizure frequency in seven out of 12 patients¹⁵.

With respect to catamenial epilepsy the figure of 22% in our data is within the range of figures in the literature, which, however, range from 9–72%². The wide range suggests that the results are highly influenced by the methods used. It is interesting that there was a (non-significant) trend for patients with higher seizure frequency to report catamenial seizures more often. This finding underlines the suggestion recently made by Crawford² that one should be cautious in interpreting the literature on catamenial epilepsy because its bias towards institutionalised patients.

In the case of alcohol our results probably reflect the inclusion of patients suffering from alcohol-related seizures not fulfilling the definition of epilepsy ('Gegenheitsanfälle'). Alcohol was typically reported by male subjects with a low seizure frequency.

It is astonishing that so many subjects believe that the weather stands in relation to their seizures, especially when contrasted with the fact that this opinion is practically completely neglected in the literature (but see^{16–18}). We do not want to speculate about possible mechanisms, but we do think that an aspect that is felt to be important by such a great number of subjects should merit more scientific awareness. The preponderance of patients living in rural surroundings might seem plausible but speculations remain provisional until these findings are replicated.

It is very important to keep in mind that the perception of a precipitant does not necessarily prove that there is a causal relationship or a temporal relationship that is more than accidentally. It only shows that the subject perceives such a relationship. In Fig. 3 we have tried to sum the factors that might build up this perception. In addition to a causal relationship the subject's theory of the disease influences the perception. Loss of self-control is one of the most important and most disturbing psychosocial consequences of epilepsy. It seems therefore reasonable that subjects try to find connections between their seizures and external or internal events that give them a feeling of predictability.

If people believe that a causal relationship exists between two events, they are likely to interpret an accidental coincidence as evidence for their beliefs. This evidence again strengthens the original belief. One example: When a patient has been told that drinking coffee triggers seizures, she or he will be prone to interpret a seizure soon after having drunken coffee as evidence for the truth of this relationship. This could be the case even if she or he has drunken coffee many times before without having suffered a subsequent seizure.

Furthermore it has been demonstrated that humans are not good in monitoring a series of events for randomness¹⁰. Therefore it cannot be assumed that subjects are competent in distinguishing temporal relationships that follow a distinct pattern from mere coincidences.

One-sixth of our subjects reported that they at least sometimes are able to abort their seizures or to influence their course. This is more than the figure of 5–6% reported in two older studies^{19,20} but comparable to the 14% of Antebi and Bird⁶. The differences are possibly due to sample characteristics and to different criteria in the studies. However, it should be noted that the belief in the ability to influence the course of a seizure might not always be based on a true physiolog-

ical phenomenon either. It could again be a function of the desire of a patient to gain control over the disease. This assumption is substantiated by the correlation with the perception of precipitants, which are themselves not under control of the subjects. Nevertheless, even in the present, where new antiepileptic drugs and advanced neurosurgical procedures have highly increased our ability to control seizures in a great percentage of epilepsy patients, one should not forget that in some patients behavioural interventions might contribute to the therapy^{21,22}.

Interestingly subjects suffering from seizures that start with an aura reported precipitants more often. This could indicate a higher susceptibility of focal seizures to external or internal triggers. This explanation, however, seems very unlikely concerning sleep deprivation usually regarded as a much more important trigger in generalised epilepsies. We can speculate that in some cases early seizure symptoms have been interpreted as precipitants or that sometimes the consequence has been mistaken for the cause.

We are aware of the limitations of our study. One problem inevitable in questionnaire studies like ours is the contamination with patients not suffering from epilepsy but from pseudo-seizures. However, even if we take a high estimate of the proportion of subjects with pseudoseizures, their report could only be responsible for a small part of our results.

The results are based on patients' reports only. This has led to restricted information concerning the classification of seizures and syndromes and other disease-related variables. A selection bias has probably been introduced, because the tendency to fill in the questionnaire and mail it to us might not be evenly distributed among patients with different severity of disease. This is reflected in the high proportion of subjects with insufficiently controlled epilepsy in our study. However, one should be aware that all studies on epilepsy populations, besides population-based studies, cover only a subset of the spectrum of the disease.

To summarise, a very high percentage of epilepsy patients believe that one or other internal or external stimulus triggers their seizures. In addition to physiological mechanisms these findings reflect lay theories of disease that are, in turn, influenced by the desire of the patients to gain control over their disease. To disentangle these aspects more thoroughly, prospective studies using seizure calendars over longer periods of time are essential. However, whatever the mechanisms are like, the great importance of seizure precipitants in lay theories of epilepsy should be considered in counselling patients with epilepsies.

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