

# Stressors at the onset of adult epilepsy: implications for practice

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**ABSTRACT** – The association between major life events and seizure frequency in patients with chronic epilepsy has previously been suggested in the literature. However, significant life events as precipitating factors for the occurrence of the first seizure have been considered but not documented. Recognition of such triggers may lead to a better understanding of the cause and mechanism of the epilepsy. Using a phenomenological approach, 19 participants were interviewed and recalled the occurrence of significant life events in the year prior to a diagnosis of generalized or focal epilepsy. There were gender and age-related differences in the types of triggering events, e.g. men tended to specify work related stressors while women generally cited relationship issues. None of the participants reported constraining beliefs about the cause of their epilepsy. Most respondents incorporated their knowledge of seizure triggers into strategies to achieve control of their epilepsy. This study highlights the potential value of questioning possible life stressors as triggers for the onset of epilepsy. Early awareness of high risk factors for seizures may lead to strategies of seizure self control by avoiding situations associated with high risks, improving lives disrupted by the uncertainty of epilepsy.

**Key words:** adult onset epilepsy, stressors, significant life events

Epilepsy is the most prevalent neurological disorder (McLin 1992). The causes are varied and often unclear. More than half of patients with adult onset epilepsy have no etiology that can be determined by the investigative means currently available. Affected persons must learn to live with a wide-range of unpredictable social and psychological difficulties often associated with the diagnosis of epilepsy, for example, isolation, stigma, discrimination and limitation of activities (Chadwick and Wolf 2003, Jacoby 1992).

Anecdotal evidence suggests that the onset of epilepsy may be triggered by important life events and that resolution of such issues as social or emotional problems may lead to improved seizure control.

It has been suggested that people with epilepsy have a “low seizure threshold” which is an intrinsic level of vulnerability to seizure activity. This threshold can be temporarily influenced by biochemical, metabolic or psychological factors (Spector *et al.* 2000). An area that has received increasing attention in the literature

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is the degree to which specific psychological changes or significant life events may act as facilitators or triggers of seizures in people susceptible to epilepsy (Antebi and Bird 1993). These are defined as the subjective perception of a life event that has taken on particular importance for that person. Although studies suggest that the stress from major and minor life events may play a role in increasing seizure activity (Temkin and Davis 1984, Webster and Mawer 1989, Haut *et al.* 2003), stress from major and minor life events that preceded a first seizure occurrence has not been reported. Holmes and Rahe (1967) initially proposed that significant life events might be a necessary, though insufficient, cause of illness presentation. More recent studies have emerged to support a correlation between stressful life events and the onset of chronic disorders such as sarcoidosis or multiple sclerosis. For example, the magnitude of stressful life events was significantly higher in patients with sarcoidosis compared with healthy controls (Yamada *et al.* 2003) and there was a significant relationship between stressful life events and the appearance of new gadolinium enhanced lesions in multiple sclerosis that varied with the type and severity of the stressor (Mohr *et al.* 2002). Thus, the life circumstances preceding onset of epilepsy merit reexamination in the light of this new evidence.

Recent studies have indicated that patients were more likely to succeed at managing their seizures if they recognized their own seizure precipitants (Spector *et al.* 2000). Early awareness of these precipitants may lead to the avoidance of high-risk situations and to the use of non-pharmacological interventions, such as relaxation and stress management techniques (Spector *et al.* 2000, 2001). This self-control is perceived rather than objectively measured. Our own clinical observations from the interdisciplinary epilepsy team at the Montreal Neurological Hospital suggest that patients with either controlled or uncontrolled seizures often spontaneously identify triggers for both focal and generalized attacks. We agree that this type of self-knowledge can potentially be harnessed as a means for patients to gain a sense of control or mastery of their lives disrupted by the uncertainty of epilepsy.

This study sought to explore 1) the life circumstances preceding the emergence of a first seizure in people with adult onset epilepsy, 2) patient beliefs about the cause of their seizures, 3) whether there were trends in patient recollections about the precursors to their first seizure, and 4) whether patients used these causal attributions of their first seizure to attempt to manage subsequent attacks.

## Methods

### Design

A phenomenological approach was used for this study.

### Subjects

Participants were recruited from the epilepsy outpatient clinic and the inpatient epilepsy-monitoring unit at the Montreal Neurological Hospital. Patients with a positive diagnosis of generalized or focal non-lesional adult onset epilepsy within the last five years, confirmed by detailed history and EEG findings, were approached to participate in this study.

Excluded from the study were individuals with a suspected or confirmed psychiatric diagnosis, cognitive impairment, individuals under public or private curatorship where a legal representative assumes decision-making responsibility or patients who were unable to provide written consent. Patients whose seizures were caused by an identified brain lesion, such as a scar, tumor or vascular abnormality were also excluded. Information about sociodemographic data, diagnosis of epilepsy, age at onset and duration of epilepsy was obtained from the patients/families and supplemented by information from their medical records.

### Procedure

The study received approval from the Montreal Neurological Hospital/Institute Research Ethics Committee. Written informed consent was obtained from the patients who agreed to participate. The epilepsy nurse clinician or social worker conducted a face-to-face interview with each participant. Each interview lasted 45 to 60 minutes and was conducted in the outpatient clinic when patients came for appointments, in the epilepsy monitoring unit when patients were admitted, or at a later date convenient for the patient/family. Patients were consulted regarding their preference to have a family member or significant other present during the interview.

A semi-structured interview guide consisted of five questions. The first question explored life events that preceded a first seizure:

– Were there any significant changes/events happening in your life around the time of your first seizure? If so, did they happen during the 12 months prior to your first seizure?

The remaining questions explored their beliefs about seizures in general, their ability to identify triggers for subsequent seizures and sense of control over them:

– What do you believe causes seizures?

– Do you think your seizures are triggered by anything in particular?

– Do you think that any of these triggers are controllable?

– Do you think there are triggers that are not controllable?

Further exploratory questions were used to allow participants to elaborate on their responses. When it was determined that the participants had completely described their responses to these questions, items from the "Life Experience Survey (LES)" (Sarason *et al.* 1978) were introduced to each participant. The LES is traditionally used as a checklist of life events where subjects rate the impact

and desirability of the life event on a 7-point scale ranging from “-3 (extremely negative)” to “+3 (extremely positive)”. In this study, only the items from the LES were used as qualitative prompts to encourage patients to remember and discuss if other life events had occurred at the time of their first seizure.

### Collection and analysis of the data

All interviews were audio taped and transcribed verbatim. One patient preferred not to be audio taped. In this case, written notes were taken during the interview and field notes recorded immediately following. The transcripts were initially read and reread to get an overall picture. Key words and phrases of each participant’s answers to the study questions were identified as meaningful units. These were then transcribed onto index cards. Each card represented an interview question and reflected the key responses of all participants. The cards were analyzed for emerging themes. These themes were then recorded on flip charts and recurrence of themes across subjects was identified. Common themes were grouped to identify similarities and differences. We then returned to the original transcripts to make sure that every theme could be identified and that all relevant material in the interviews was reflected in the themes. There was full consensus between the contributors of this study on the themes generated. A research consultant external to the study but who was familiar with qualitative analysis then validated the final analysis. Initially 14 patients were interviewed, the data were analyzed and themes identified. Subsequently another five patients were interviewed and

further data analysis did not reveal any new themes. It was felt that data saturation had been achieved.

## Results

A total of nine men and ten women, of varying occupational backgrounds, participated in this study (*table 1*). The mean age of the men was 42 years (range 18-59) and that of the women was 32 years (range 18-53). The time elapsed since diagnosis was 3 to 60 months, with an average of 29 months for the men and 21 months for the women. The following are results of the study questions.

### - Were there any significant changes/events happening in your life around the time of your first seizure? If so, did they happen during the 12 months prior to your first seizure?

All participants reported significant life events in the 12 months prior to their first seizure. Different themes were noted between men and women. For women, the themes varied according to their developmental stage in life. Men (n = 7/9) primarily reported work related stressors such as job loss, change or increase in job responsibilities, starting a new job and looking for a new job because the current one was intolerable. *“I was let go from my previous job and had just started working in a smaller firm”*. Young adult men, aged 18 to 29 reported stress associated with decisions about career choices and social relationships. *“I had just left Europe and could no longer go to college. I had to look for a job here. I left behind good friends.”* Several men reported non-career related stressors, such as marital problems, conflict with children and social iso-

**Table 1.** Sample demographics.

Subject	Sex	Age	Time since seizure onset	Occupation
1	F	31	36 months	PHD student
2	F	26	6 months	Speech language pathologist
3	M	59	11 months	Business executive
4	M	46	60 months	Business executive
5	M	35	24 months	Mediator
6	F	46	6 months	Homemaker (Univ. education)
7	F	53	36 months	Office worker
8	M	40	60 months	Accountant
9	F	23	60 months	Student
10	F	19	3 months	College student
11	M	50	12 months	Office worker
12	F	27	24 months	University student
13	F	43	6 months	Sales clerk
14	F	35	36 months	Home maker (Univ. education)
15	M	20	6 months	Factory worker
16	M	18	3 months	Student
17	M	29	24 months	Maintenance worker
18	M	32	4 months	Business manager
19	F	18	18 months	College student

lation when significant other persons were present during the interviews.

Young adult women (in their 20s) identified their struggles according to the completion of developmental tasks and facing multiple stressors. One respondent reported: *"My first seizure occurred right after my honeymoon. I was in school, holding down two jobs, my family had moved away. I was struggling with it all."* Another young woman described the following: *"I was upset about my career choice - not getting into the program I wanted. I grieved giving up what I really wanted to do. That summer, I moved out of town with my boyfriend, started a new job, and then we broke up and I moved again."*

A participant in her 30s talked about her first seizure occurring after multiple stressors: the birth of her first child, the recent death of a close friend and a change in employment status. Women in their 40s/50s identified major losses and disruption of family relationships. *"My parents died in the year leading up to my first seizure, my child died in the year before that. My husband was facing bankruptcy. I also lost my job and there were problems with my parents' will that caused major family conflicts."* A second woman reported: *"I was still dealing with the death of my son several years ago, when my parents died also. I suffered a heart attack and then developed diabetes. You can say I've had some big losses"*.

#### **- What do you believe causes seizures?**

Both men and women identified stressful life states as the cause of their seizure activity. Men attributed stress to the environment of the workplace and being the sole provider for the family, as possible causative influencers. The older women in the sample reported *"stress from health problems and losses"* and *"anguish at receiving bad news and having to keep emotions inside, tied up in knots."*

Similarly, both men and women perceived there might be the possibility of a biological causative factor. Some men talked about biological factors causing seizures. *"I believe it's more body structure, my metabolism"* or *"A chemical imbalance of some sort."* Others described lack of sleep or excessive alcohol intake. Young women in the sample (3/6) also referred to *"being predisposed because of biological and environmental factors"*, *"something in my brain short circuits"* or *"an image of my body taking a wrong path which is out of my control"*.

#### **- Do you think your seizures are triggered by anything in particular?**

The main triggers identified by both men and women were sleep loss and stress. The majority of the men identified work related stress. The women in the sample reported worries related to school, work and relationships. The women also focused on the stress of strong emotions, difficulty asserting oneself in family conflict situations and stress from grief and loss. Stressors for ongoing seizures were similar to those described as preceding their first seizures. They were not specifically asked, however, if this was the case. Approximately two thirds of respondents

were able to identify specific triggers occurring more immediately before a seizure; namely, sleep loss, alcohol consumption, missing anti-epilepsy medication, exercise and watching video games.

#### **- Do you think that any of these triggers are controllable?**

Most of the participants perceived their seizure triggers to be within their control and developed coping strategies to exert their influence. Themes common to all participants were setting limits, getting adequate sleep and communicating more effectively to reduce stress. The male respondents referred to *"delegating more at work"*, *"decreasing workload"* and *"communicating more effectively to decrease tensions in the workplace"*. Getting more sleep and controlling alcohol intake were also mentioned. The women talked about *"using relaxation to decrease stress"*, *"setting limits regarding what I take on"*, and *"getting support in becoming more assertive and adopting good lifestyle habits"*.

#### **- Do you think there are triggers that are not controllable?**

Interestingly, participants also recognized that there were limits to their ability to control certain factors. For example, 56% (5/9) of the men in the sample reported *"genetics are out of my control"*, *"it is my work ethic that stops me from reducing my responsibilities at work"* and *"wanting to engage in activities that I know are risky for seizures"*. Similarly, 40% (4/10) of the women responded the following: *"you can't control things that happen to you"*, *"you can't control the difficult behaviors of others"* and *"you can't control the unpredictable nature of seizures despite good life habits"*.

## **Discussion**

This study sought to explore patient perceptions of the relationship between significant life events and the onset of epilepsy, and the extent to which recognition of this relationship may be useful for managing future seizure activity.

When prompted to think about significant life events that might have preceded their first seizure, participants often recalled a cluster of life events that were significant for them at the time. Although clinical practice suggested that some patients spontaneously reported a first seizure in the context of coping with significant life events, the systematic reporting of such a finding by all the participants in this study was striking. A limitation in this study is that patients were not asked about how these life events compared with significant events/stressors in the years before the 12 months preceding the onset of the epilepsy. This could be a point of interest in future work.

The effect of a chronic illness on the completion of developmental tasks associated with the different stages of life is well described in the literature (Wright and Leahey 1994). In our study sample the struggle to complete developmental tasks emerged as a recurrent precursor to the onset of

chronic illness. Young adult men and women (in their 20s) described struggling with career choices and peer relationships. Older women reported family tensions associated with juggling multiple role demands. It is noteworthy however, that whereas the majority of life events associated with increased seizure frequency discussed in the literature are associated with a negative valence (Temkin and Davis 1984), our findings indicated that even positive life events such as the birth of a child or the opportunity of a scholarship were considered stressful events that sometimes preceded a first seizure. Positive life events were reported by 3 of the 19 participants interviewed.

In addition, our results indicate that there may be gender differences in the types of life events reported by men and women. The men in the sample identified primarily work related stressors, and only included family or social stressors at the prompting of a female significant other, *i.e.* a wife or mother. In contrast, women in the sample predominantly described stressors associated with ruptured family relationships and coping with multiple responsibilities. Matud *et al.* (2004) also reported these differences in stress between men and women. They found that women more frequently reported family and health related events experienced by other people in their environment and men reported events related to work and finances.

With respect to causal attributions of epilepsy, 50% of patients in this study identified biological causes for seizures. The same response was given by 40% of patients in response to what causes seizures in general and what triggers their particular seizures. This may be because the phrasing of the questions did not distinguish between beliefs about etiology of epilepsy and triggers for recurrent seizures. None of the study participants reported any misconceptions or unusual beliefs about the etiology of their illness as described in the literature, which may have subsequently affected how they coped with their illness (Wright and Leahey 1994, Wright *et al.* 1996). This may be because the participants who self-selected themselves to enter the study may have had a higher level of education than many of our other clinic patients with refractory seizures and other co-morbidities. In the future, it would be interesting to further explore the causal attributions of epilepsy in patients who have a wider range of educational and social backgrounds.

Similar to Spector's study in which over 90% of their sample could identify at least one seizure precipitant, our findings indicate that the majority of respondents were also able to identify their seizure triggers (Spector *et al.* 2000). Almost all patients interviewed identified stress as a precipitant to their first seizure and ongoing seizures. That being said, they were not specifically asked if the same type of stressful events that preceded their first seizure triggered recurring seizures. However, when we compared their responses to these questions (significant

life events prior to a first seizure and triggers for ongoing seizures), we found that the themes were similar in more than one third of respondents. That is, work related stress for men and relationship stress for women, which reflect situations associated with a higher risk of seizures *versus* immediate seizure triggers. As mentioned, approximately two thirds of patients were also able to identify specific triggers occurring more immediately before their seizures. When asked which triggers were uncontrollable, one participant recognized that his work ethic prevented him from delegating some of his responsibilities despite recognizing that his workload was a prime seizure trigger for him. Another described wanting to engage in activities that he knew increase the risk of seizures, as "*being uncontrollable*". Hence, the ability to identify triggers and strategies to control them did not always translate into changing behaviors.

Spector *et al.* (2001) demonstrated that individuals who believed strongly in their own ability to control or influence their environment and bring about a desired outcome were more likely to identify their seizure precipitants, and seek out situations in which seizures were less likely to occur, compared to another group of individuals who thought they had less control over their circumstances. Patients with high perceived self-control did not seem to be influenced by how long they had epilepsy, those with low perceived self control beliefs were more strongly influenced by their epilepsy history, feeling less in control as they continued to live with poorly controlled seizures (Spector *et al.* 2000). Although our study participants appeared to demonstrate an internal locus of control, and were able to distinguish areas of their lives that they could and could not control, longitudinal studies are needed to further explore how patients adjust to the unpredictable nature of their attacks over a longer period of time.

## Conclusion

The identification of possible precursors or triggers to a first seizure may provide useful information that may be used to learn more about the causes and possible control of subsequent attacks. This study showed that when patients were asked about their life experience/context at the onset of a seizure disorder, they realized that their seizure disorder often emerged at a time when they were overwhelmed by stressors associated with significant life events and challenges. Clinicians may engage patients in important discussions regarding their beliefs about what is happening and why. This can promote discussions incorporating information about the context of a first seizure into strategies to promote control. As stated by Jacoby (1992), patients and families can be encouraged to develop skills in observing seizures, identifying circumstances and managing stress and other triggers, gaining a

sense of mastery over their illness and its treatment as a key component of coping with it. Health care professionals are in a privileged position to structure those meaningful, therapeutic interventions that can help patients find personal ways to improve seizure control. □

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