



## Spontaneous strategies for psychological control of seizures

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### ARTICLE INFO

#### Article history:

Received 9 August 2012  
Revised 6 December 2012  
Accepted 6 January 2013  
Available online xxx

#### Keywords:

Seizure control  
Epilepsy  
Spontaneous strategies  
Seizure scales  
Self-management

### ABSTRACT

The present research explored the strategies individuals with epilepsy use to manage seizure activity by using a survey method ( $n = 105$ ). Analysis suggests that participants' strategies are more likely cognitive or behavioral in nature, rather than emotional. Furthermore, strategy usage varied by whether participants experienced a global perception or an immediate perception of seizure susceptibility. Cognitive strategies were more likely used in response to immediate awareness of seizure risk ( $p < .01$ ), whereas behavioral strategies corresponded to a global awareness of risk, though this finding did not quite reach significance ( $p = .06$ ). The present research 1) provides new information regarding the relationship between awareness of seizure susceptibility and strategy use by individuals with epilepsy to manage seizure activity and 2) developed two new scales (Cognitive, Behavior, & Emotional Strategies for Seizure Control Scale and Perception of Seizure Control Scale) for future research and clinical use.

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### 1. Introduction

Epilepsy is the third leading neurological disorder behind Alzheimer's disease and stroke and is marked by the occurrence of two or more unprovoked seizures. Approximately one out of ten people worldwide will experience a seizure sometime in their life, but only between 1 and 3% will be diagnosed with epilepsy. While medication is helpful in managing seizures for most, 30% of individuals with epilepsy do not receive respite from seizures with antiepileptic medications [1].

Throughout the past decade, research on the psychological management of seizures has steadily gained greater attention [2,3]. It is now known that nearly half of individuals with epilepsy report an ability to terminate, prevent, or reduce the impact of some of their seizures [2–11]. However, the exact strategies employed by individuals with epilepsy to abort seizure activity as it is occurring are largely unknown. Furthermore, the extent to which these strategies may be affected by an individual's level of seizure susceptibility has not been explored. Research in this area may benefit most individuals with epilepsy, especially the 30% who are not helped by traditional antiepileptic medication. The present research set out to explore these strategies by using a survey method. Ultimately, this research led to the development of two novel scales (Cognitive, Behavior, & Emotional Strategies for Seizure Control Scale and Perception of Seizure Control Scale). In order to develop the items for the scale, a pilot study was conducted.

### 2. Pilot study

Survey questions were developed through a pilot study by using one-on-one interviews with 9 volunteer individuals with well-managed epilepsy. Interviews were conducted individually with participants and ranged in length between 25 and 60 min. A semi-structured interview technique was used. Interview questions included a broad range of topics including 1) history of seizures; 2) behavioral, emotional, and cognitive experiences before, during, and after seizures; 3) issues of psychological control of seizures; and 4) perception of life experiences, both positive and negative relative to having a seizure disorder. Table 1 describes the emergent themes obtained from the interview transcripts.

Three broad themes relative to seizure control were identified in the pilot study. These themes are as follows: 1) Perceived psychological control of seizure activity was contingent upon awareness of seizure risk, such that the greater the awareness the greater the perceived control; 2) Participants identified two types of seizure risk awareness: a global or general awareness and an immediate awareness or aura; 3) Spontaneous strategies used for seizure control were specific to the type of risk awareness, such that individuals with epilepsy experiencing global awareness were more likely to use behavioral strategies to manage seizure activity, whereas participants experiencing an aura or immediate sense of seizure risk were more likely to use cognitive strategies.

#### 2.1. Participant demographics

Adult volunteers ( $n = 105$ , 35 males and 70 females) aged 18–69 ( $M = 32.5$ ) gave their informed consent to take part in an online survey. Recruitment was made through the Epilepsy Foundation support groups and listserv and online epilepsy support groups. The ethnicity of the participants was identified as follows: 82.9% Caucasian, 4.8%

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**Table 1**  
Pilot study.

| Theme  | Participant responses  |
|--|--|
| Psychological control of seizures is contingent upon awareness of seizure risk         | The majority of participants (77%) believed they had psychological control over their seizures in some way. However, perception of control was related to participants' initial awareness of their seizure risk.   |
| Participants identified two types of seizure risk awareness                            | Global seizure awareness:<br>General sense or assessment of how prone they feel with regard to having a seizure. This tends to be based on knowledge of seizure triggers, <i>i.e.</i> , <i>I'm probably going to have a seizure, I'm sick.</i><br>Immediate seizure awareness (aura):<br>Seizure risk identified immediately preceding seizure onset, usually described as sensory specific experiences, <i>i.e.</i> , <i>I'll get hot, I'll get a headache, I'll just have a lack of energy. I won't understand what somebody is saying to me. I'll have physical awareness but not cognitive awareness (beyond the physical sensations).</i>   |
| Spontaneous strategies for seizure control were specific to the type of risk awareness | Behavioral strategies emerged in response to a global seizure susceptibility<br>In response to global seizure awareness participants described 1) limiting risky activities or behaviors and 2) engaging in prophylactic behaviors or activities associated with making a seizure less probable, <i>i.e.</i> , eating healthy and sleep hygiene<br>Cognitive strategies emerge in response to an immediate risk or aura<br>In response to immediate risk or aura, strategies were more likely to be described cognitively. This cognitive re-focusing tended to be on internal rather than on external or environmental stimuli. Although used in response to a perceived immediate risk or experience of an aura, cognitive strategies were not always successful in deterring a seizure. However, participants did perceive that in engaging in these cognitive strategies, they may have limited the progression or severity of seizures. |

Asian American/Pacific Islander, 1.9% African American, and 9.5% other. Approximately 90% of the participants were currently taking at least 1 antiepileptic drug. Approximately 47% of the participants were currently employed. Participants' last seizures ranged from "occurring 10 min ago" to "over 10 years ago".

Participants were asked to rate the level in which their epilepsy interferes with their life. Twenty-three percent of the participants stated that epilepsy interferes with much of their daily life. Thirty-five percent stated that it interfered somewhat. Approximately 26% stated that their epilepsy did not interfere "too much" with their daily life. Only 16% of the participants stated that their epilepsy did not interfere with their daily life. All participants were asked to state the type of seizures they most commonly experienced. Seizures were classified as (7.6%) generalized absence type, (.8%) generalized atonic type, (5%) generalized myoclonic type, (67.2%) generalized tonic-clonic type, (1.7%) simple partial type, and (17.6%) complex partial type. With regard to seizure frequency, 8.9% of the participants experienced multiple seizures per day, 9.7% experienced at least one seizure per day, 4.8% experienced seizures once every couple of days, 5.6% experienced one seizure every week, 8.9% every couple of weeks, 11.3% every month, and 16.9% every couple of months, and 33.9% experienced infrequent seizures. About half of the participants (54.3%) reported that they had some control over the onset or severity of their seizures.

## 2.2. Survey method

Themes from the pilot study were considered and adapted to allow for in-depth study utilizing an online survey format. The survey consisted of both qualitative questions in which participants were instructed to enter their own response and, in the form of rating, their degree of seizure awareness, strategies used to manage seizures, and their level of control on a Likert scale.

Participants accessed the online survey individually through a secure survey. All survey responses were anonymous. Following informed consent, participants completed a series of questions related to global seizure awareness and immediate seizure awareness, strategies for seizure control, and perception of seizure control.

## 2.3. Assessment of seizure awareness

Global seizure awareness and immediate seizure awareness were each assessed independently by using a single-item question with participants indicating their agreement using a four-point Likert scale. For global awareness, participants had the following response:

*"I usually have a general sense of how prone I am to having a seizure."*  
For immediate seizure awareness, participants responded with: *"I usually experience an aura (or warning sign) just before I have a seizure."*

## 2.4. Cognitive, Behavior, & Emotional Strategies for Seizure Control (CBES-SC) Scale

Participants' strategies for managing seizures were assessed using the Cognitive, Behavior, & Emotional Strategies for Seizure Control (CBES-SC) Scale. This measure was developed for this research. This nine-item scale asks participants to rate their level of agreement using a four-point Likert scale. Three items in this scale corresponded to cognitive strategies, for example, *"When I feel a seizure starting I focus my attention on something in my environment (i.e., what someone is saying or a song on the radio)."* Another three-item scale assessed behavioral strategies, for example, *"I control the severity of my seizures by preparing myself for the effects of the seizure (i.e., sitting down or bracing)."* The final three items in the scale corresponded to emotion regulative strategies such as, *"When I feel a seizure starting, I try to make myself feel calmer."* For a complete list of survey questions, please see Table 2. The

**Table 2**

Survey questions for strategy use.

| Cognitive, Behavior, & Emotional Strategies for Seizure Control (CBES-SC) Scale   |
|---|
| <i>Cognitive</i>  |
| 1. I control the severity of my seizure by changing the way I think ( <i>i.e.</i> , more positively) or what I am thinking about.                     |
| 2. When I feel a seizure starting I focus my attention on something in my environment ( <i>i.e.</i> , what someone is saying or a song on the radio). |
| 3. When I feel a seizure starting I focus my attention on something in my mind ( <i>i.e.</i> , a phrase or a prayer).                                 |
| <i>Behavioral</i>   |
| 4. I control the severity of my seizures by preparing myself for the effects of the seizure ( <i>i.e.</i> , sitting down or bracing).                 |
| 5. When I feel susceptible to having a seizure I avoid putting myself in risky situations ( <i>i.e.</i> , driving or climbing a ladder).              |
| 6. In order to prevent seizure activity I try to eat right, exercise, and take care of myself.  |
| <i>Emotional</i>  |
| 7. When I feel a seizure starting, I try to make myself feel more calm.   |
| 8. When I feel a seizure starting, I try to make myself feel more positive emotions.  |
| 9. When I feel susceptible to having a seizure, I try to make myself feel more neutral (neither good nor bad).  |

**Table 3**  
Survey questions for perceived control.

| Perception of seizure control scale  |
|--|
| 1. When I feel a seizure starting there is nothing I can do to control it. <sup>a</sup>                  |
| 2. I feel I have some control over the severity or onset of some of my seizures.                         |
| 3. I am directly responsible for my seizure activity getting better or worse.                            |
| 4. Whether my seizure activity stops or lessens is a matter of luck or fate alone. <sup>a</sup>          |
| 5. No matter what I or anyone else does, if I feel a seizure starting it is going to start. <sup>a</sup> |
| 6. If my epilepsy worsens it is probably because I have not been taking proper care of myself.           |

<sup>a</sup> Denotes reverse score items.

CBES-SC scale was found reliable by producing a Cronbach's alpha of .862.

### 2.5. Perception of Seizure Control Scale

Participants' level of perceived control (internal locus *versus* external locus) was examined with the Perception of Seizure Control Scale, a new scale developed for the purpose of this research. This scale is composed of six questions in which four were adapted from Form C of the Multidimensional Health Locus of Control (MHLC) scale for specificity to epilepsy (Table 3). This six-item scale was also measured on a four-point Likert scale and resulted in a Cronbach's alpha of .683 suggesting adequate reliability. The six items of the scale were entered into a factor analysis with a varimax rotation. The Kaiser–Meyer–Olkin measure of sampling adequacy was .719, indicating that the scale was adequate for factor analysis. Three items representing perception of internal control loaded on one factor, while the remaining three items corresponding to perception of external seizure control loaded on the second factor. Combined, these two factors accounted for 57.69% of the variance.

## 3. Results

### 3.1. Spontaneous strategies for seizure control were specific to degree of awareness

Three separate chi-squares were calculated by comparing the frequency of cognitive, behavioral, and emotional strategies for participants with high or low levels of seizure susceptibility awareness. For participants with high awareness, there was no significant difference between high and low cognitive strategy use; these participants were just as likely to endorse high cognitive strategy use (40% of the participants) or low cognitive strategy use (45.7%). However, a significant interaction was found ( $\chi^2(1) = 8.51, p < .01$ ) for cognitive strategies, such that participants with low levels of awareness had low cognitive strategy use (13.3%), whereas participants with high levels of awareness had high cognitive strategy use (1%).

A significant interaction was also found for behavioral strategies ( $\chi^2(1) = 24.75, p < .001$ ) when awareness was categorized as high and low. There were more participants with high awareness who endorsed high behavioral strategy use (78%) to manage seizure activity than participants with low awareness who endorsed high behavioral strategy use (5.7%). Finally, a significant interaction was found for emotional strategies ( $\chi^2(1) = 14.26, p < .001$ ). There were more participants with high awareness of seizure activity who reported high emotional strategy use (64.8%) than individuals with low awareness who reported high emotional strategy use (3.8%).

### 3.2. Strategies vary by immediate (i.e., aura) but not general seizure risk awareness

Chi-square was also used to examine strategy use across participants that had an immediate sense (i.e., aura) or general sense of seizure

susceptibility. Participants with an immediate sense of awareness were more likely to use cognitive ( $\chi^2(1) = 12.07, p < .001$ ) or behavioral strategies ( $\chi^2(1) = 7.37, p < .01$ ) than emotional strategies ( $\chi^2(1) = 2.22, p > .05$ ). There was no statistically significant finding that strategies were specific to general awareness. However, there was a trend for participants reporting a general sense of awareness to report high behavioral strategy use ( $p = .06$ ) and emotional strategies ( $p = .06$ ) than cognitive strategies ( $p = .09$ ).

### 3.3. Psychological control of seizure activity is contingent upon awareness of seizure risk

A simple linear regression was calculated to predict participants' level of perceived control over seizure activity based on their total awareness of seizure susceptibility. A significant regression equation was found ( $F(1,103) = 57.18, p < .05$ ), with a  $R^2$  of .221 and a Durbin–Watson of 2.09. It appears that the greater the participants' awareness of seizure susceptibility, the greater their perceived control over seizures.

## 4. Discussion

The research reported here is an exploratory analysis of spontaneous and uncoached strategies for seizure abortion for individuals with seizure disorders. The purpose of this research was to gain an understanding of seizure disorders as they are experienced and described by individuals. For that reason, seizure classification and diagnosis was not a main focus for grouping participant responses. Instead, the emergent themes across individual seizure narratives in a pilot study were considered and used to guide a survey approach of the topic. With regard to issues of control, seizure narratives illustrated a marked distinction across a number of indicators: First, participants differed in terms of whether they perceived an awareness of seizure susceptibility. Some participants were able to detect seizure risk as they discussed warning signs while others were not. Second, among those participants who had an initial awareness, a distinction was made between a general susceptibility and an immediate risk or aura. Third, the spontaneous strategies discussed among these participants also separated among the risk level (general susceptibility *versus* immediate risk). Initial exploratory investigation discovered that individuals with immediate awareness of seizure risk were more likely to use cognitive strategies, whereas individuals with a more general sense of seizure risk were more likely to use behavioral strategies. Further survey investigation revealed that individuals with immediate awareness of seizure risk were likely to use cognitive or behavioral strategies but not emotional strategies. Additionally, a trend was present for individuals with a general sense of seizure risk to use more behavioral than cognitive strategies, though this finding did not quite reach significance.

The results of the present research indicate that self-management strategies can be effective for some individuals who suffer from epilepsy. Fifty-four percent of the participants in this study indicated that they used self-management strategies to control seizures. Future research could use this information to develop new self-management programs to teach individuals with epilepsy to use similar strategies.

### 4.1. Clinical and research implications and directions for future research

The current research findings have implications for understanding psychological seizure control from the perspective of the participant. From the participants' point of view, a seizure may not always be viewed as the result of a failure of control. For example, if the participant had no previous warning of the seizure, he or she would have not had the opportunity to attempt to control the situation. In addition, an individual may view a less severe seizure as a successful outcome of control. Continued research in this area will allow for a greater understanding of seizure disorders as they are experienced on an individual level and allow for this perspective to be integrated into a clinical model for epilepsy.

Initial exploratory interviews proved important for establishing a connection between awareness type and spontaneous strategies used for psychological control of seizures, which guided more quantitative exploration using the current survey method. However, future research is still warranted. In particular, the present findings could be used to inform additional quantitative approaches to better understand the strength of the relationships among seizure awareness, perception of control and spontaneous strategy use and its potential relationship to psychological distress (namely depression and anxiety) and quality of life. Additionally, future research should explore individuals of varying duration of the disorder (*i.e.*, recently diagnosed or not) to determine if awareness of seizure susceptibility increases with time and whether strategies change as a result of increased awareness. Such an approach could extend the generalizability of the present findings as well as allow for a better understanding of factors that contribute to strategy success.

The present study has several limitations. Primarily, this is a retrospective self-report study; thus, the issue of recall bias cannot be ignored. This topic has previously been investigated using 'diary studies.' Participants who have not experienced seizure activity recently are less likely to be accurate in their responses [12]. Additionally prospective diary studies have found that participants are likely to underreport seizure activity in the post-ictal state [13], and many individuals with epilepsy may not be aware of all their seizures [14]. The current study addressed this concern by reporting participants' seizure frequency. Another limitation of the current study is that it did not distinguish whether participants engage in the spontaneous self-management strategies during the pre-ictal state or during an aura. Research suggests that self-management strategies may be more effective during the transition between pre-ictal and ictal states [15]. Although this would be critical to include in future investigation, the current study sought to study self-management strategies from

the vantage of a participant's point of view with specific interest in how self-management strategies shifted based on awareness type.

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