

Seizure emergency plans: Patient results from a cross-sectional epilepsy survey [☆]

James W. Wheless ^a, Ranjani Manjunath ^b, Stephanie J. Phelps ^a, Miya R. Asato ^c, Raj D. Sheth ^d,
Collin A. Hovinga ^a, Jesus E. Pina-Garza ^e, Lisa S. Haskins ^f, Wendy M. Zingaro ^{f,*}

^a University of Tennessee Health Science Center, Memphis, TN, USA

^b GlaxoSmithKline, Research Triangle Park, NC, USA

^c Children's Hospital of Pittsburgh, Pittsburgh, PA, USA

^d University of Wisconsin, Madison, WI, USA

^e Vanderbilt University, Nashville, TN, USA

^f Harris Interactive, Rochester, NY, USA

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ABSTRACT

Guidance for seizure emergency plans exists, although their impact and extent of use in patients with epilepsy are undetermined. This study's primary purpose was to measure the estimated use and content of seizure emergency plans. Secondary objectives included measuring: disease severity, quality of life, productivity, and adherence among patients with and without a plan. An online survey was conducted among 408 patients with epilepsy (ages 18–64) who took one or more antiepileptic drugs. Only 30% of patients reported having a plan, which included avoiding injury, notifying a physician, resting/relaxing, and seeking emergency assistance. Those with a plan were more likely to have experienced more seizures in the past year, to have missed school/work, to have incurred injury, to have visited the ER, to have been hospitalized, to fear additional seizures, and to have lost a job. Seizure emergency plans appear to be reserved for adults with more severe disease, but there may be clinical benefits to developing a plan for all adult patients with epilepsy.

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1. Introduction

More than 2.5 million Americans have epilepsy or seizure disorders, and approximately 200,000 new cases are reported each year [1–4]. Of great concern is the threefold risk for mortality among those with epilepsy compared with the general population [5]. To help prevent the consequences of breakthrough seizures or recurrent seizures, a crucial element of optimal epilepsy care includes the implementation of a seizure emergency plan [4,6–14]. A seizure emergency plan is a predetermined set of instructions to assist patients/caregivers in preventing or reducing the consequences associated with a seizure [7]. Typical seizure plans may guide rescue medication use, address activities, or the need to seek medical care. These plans help to ensure that patients with epilepsy receive optimal, effective, and rapid treatment [8,11,12,14].

There are several benefits to developing and adhering to a seizure emergency plan. First, following a prescribed plan reduces seizure-related morbidity and mortality, as well as the potential neurological damage from delayed treatment [8,10–13]. Rapid treatment may also prevent a seizure from progressing into status

epilepticus. Second, a plan aids others in accurately identifying typical or atypical seizure patterns, thereby minimizing delayed treatment. Finally, adherence to a seizure emergency plan helps avoid visits to the emergency room or hospital and may reduce costs associated with epilepsy [8,11,12].

The success of a seizure emergency plan is dependent on the participation of a wide variety of medical and nonmedical individuals. Not only must the physician, patient, their caregivers, and family members participate, but success may also depend on participation of emergency personnel, other health care professionals, and school or work professionals. Seizure emergency plans are effective only to the extent that all those involved are aware of the plan, are knowledgeable of its contents, and commit to follow the plan [6–9,11,12,14].

As seizure emergency plans are used by individuals with varying medical literacy, plans should be easy to comprehend, include basic seizure first-aid instructions, and specify treatment directives based on the progression or severity and frequency of the seizures [6–8,11,12]. Seizure emergency plans should also include instructions for postictal care and delineation of critical circumstances that require contacting emergency services [7,8,11,12]. These plans should be unique to the individual patient, as instructions will vary based on epilepsy history, treatment regimens, and other factors [8,11].

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* Corresponding author. Address: Harris Interactive, 60 Corporate Woods, Rochester, NY 14623, USA. Fax: +1 585 214 7108.

E-mail address: wzingaro@harrisinteractive.com (W.M. Zingaro).

In a controlled prospective study conducted by Gunter et al., the benefits of having a disease management intervention program that included a seizure emergency plan were clearly demonstrated [9]. Patients who received the intervention showed marked improvement in emotional well-being, seizure worry, and overall quality of life compared with those who did not receive the intervention [9].

Although there is some indication about the appropriate content and benefits of seizure emergency plans, we are unaware of published literature that quantifies the use of seizure emergency plans in a “real” world setting. Furthermore, there is no information characterizing the patient population that typically is instructed on seizure plans. The purpose of our study is to measure the estimated use of seizure emergency plans and understand the content of these plans in adults diagnosed with epilepsy. Secondary objectives include identifying key differences in disease severity, seizure control, quality of life, productivity, and adherence in patients with and without a plan.

2. Methods

2.1. Sample

A cross-sectional online survey was conducted among adult patients with epilepsy, regardless of whether the patients had a seizure plan. Patients were recruited through Harris Interactive's HarrisPollOnline (HPOL), which is a multimillion member online panel. To qualify, patients had to be U.S. citizens and residents, between the ages of 18 and 64, self-reported as diagnosed with epilepsy or seizure disorder, and currently taking at least one antiepileptic drug (AED). Between April 19, 2007 and May 10, 2007, a total of 2796 individuals were invited to participate in the research and a total of 408 patient interviews were completed. As encouragement for participation in this study patients received points in a Harris Interactive incentive program.

2.2. Survey

The survey was designed and revised after discussion and review by the study investigator panel composed of epileptologists, pharmacists, outcome researchers, and statisticians. The survey contained questions regarding demographics, seizure history (type and frequency), current AEDs, seizure-related morbidity/impairments (e.g., hospitalization, ER visits, work history), quality of life, self-reported adherence, and the patient–physician relationship. For the purpose of this study, a seizure plan was defined as a plan recommended by the patient's physician detailing steps to be taken when the patient has a seizure. Patients were asked questions regarding seizure plans with this definition in mind. The average survey duration was 23 min (SD = 13.9).

2.3. Statistical analysis

Patient data were weighted using propensity score weighting to reflect the adult epilepsy population in the United States. This is a method used to correct for attitudinal differences typically found in online respondents [15]. Variables used to weight data included age, sex, race/ethnicity, education, region, and household income. The propensity score weighting specifically allowed for adjustment of attitudinal and behavioral differences between those who are online and those offline, those who join online panels and those who do not, and those who responded to this survey and those who did not.

Descriptive statistics were calculated using *t* tests, and significance was defined as an $\alpha < 0.05$ to compare patients with a seizure emergency plan with those without a seizure emergency plan.

3. Results

3.1. Demographic and clinical characteristics

A total of 408 patient interviews were completed, yielding a response rate of 28% and a qualification rate of 52%. Respondents were distributed throughout the United States as evidenced by only 13 zip codes being shared by two respondents each. On average, patients were 43 years of age (SD: 11.7), 51% were male, and 81% were white. Sixty-one percent of patients had at least a college degree. Sixty-three percent of patients with a seizure emergency

plan and 55% of patients without a seizure emergency plan were married or living with a partner. All other demographic characteristics can be found in Table 1.

Table 2 summarizes the clinical characteristics of the patient population. Patients reported that they began experiencing seizures at the age of 20 (SD = 14.2) and self-reported being diagnosed with epilepsy or a seizure disorder at 21 years of age (SD = 13.7). When asked with what type of seizures they were diagnosed, more than half indicated they were diagnosed with generalized seizures and were maintained on only one seizure-related medication. Forty-four percent of patients reported experiencing at least one seizure in the past year, and 40% reported missing a dose prior to the onset of a seizure.

Thirty percent of patients reported having a seizure emergency plan. Those with and without a plan were found to be similar with respect to age, race, educational achievement, and income (Table 1), as well as age at onset of seizures, and age when diagnosed with epilepsy (Table 2).

3.2. Estimated use and content of seizure emergency plans

Most patients with a seizure emergency plan (74%) reported that they always follow their plan, 26% said they sometimes follow their seizure emergency plan, and less than 1% said they do not follow their plan. The content of the seizure emergency plan was di-

Table 1
Demographic Characteristics

Variable	Total patients (n = 408)	With seizure emergency plan (n = 112)	Without seizure emergency plan (n = 296)
Age			
18–19	1%	—	2%
20–29	15%	15%	14%
30–39	22%	23%	21%
40–49	31%	31%	32%
50–59	23%	27%	21%
60–64	9%	5%	10%
Mean	43.3	43.5	43.3
Race			
White	81%	81%	81%
Black/African-American	5%	3%	5%
Hispanic	5%	4%	6%
Other	7%	8%	7%
Decline to answer	2%	4%	1%
Gender			
Male	51%	61%	47%
Female	49%	39%	53%
Marital Status			
Single, never married	29%	29%	29%
Married	52%	59%	49%
Divorced	9%	6%	11%
Separated	2%	1%	2%
Widowed	1%	^a	2%
Living with partner	6%	4%	6%
Highest Level of Education			
Less than high school	1%	—	1%
High school	38%	40%	38%
College	50%	49%	50%
Graduate school	11%	11%	11%
Income			
<\$15,000	17%	15%	18%
\$15,000 to \$34,999	25%	26%	24%
\$35,000 to \$49,999	14%	17%	12%
\$50,000 to \$74,999	12%	13%	12%
\$75,000 to \$99,999	11%	10%	11%
\$100,000+	10%	4%	12%
Decline to answer	12%	15%	11%

^a Less than 1%.

Table 2
Clinical Characteristics

Variable	Total patients (n = 408)	With seizure emergency plan (n = 112)	Without seizure emergency plan (n = 296)
Mean age seizures began	20.0	18.9	20.5
Mean age of diagnosis	20.9	20.4	21.2
Type of seizures			
Partial (focal)	12%	5%	15%
Generalized	57%	57%	56%
Both	25%	35%	20%
Not sure	7%	2%	9%
Number of seizures in past year			
None	56%	50%	59%
One to four	19%	19%	20%
Five to nine	8%	8%	8%
Ten or more	17%	24%	13%
Number of seizure related medications			
One	61%	55%	64%
Two	24%	27%	23%
Three	11%	14%	10%
Four or more	3%	5%	2%
Not sure	1%	0%	2%
Mean	1.6	1.7	1.5
Change in seizure frequency as a result of current medication			
Increased	5%	6%	4%
Remained the same	29%	38%	25%
Decreased	66%	56%	71%
Missed dose prior to onset of seizure (%Yes)	40%	51%	36%

verse, but included attempts to reduce provoking factors, seeking medical assistance, avoiding injury, contacting a spouse/partner, and taking an extra dose of an AED (Fig. 1).

3.3. Disease severity

Compared with those without a seizure emergency plan, those with a plan differed significantly in the type of seizures they experienced as well as in the number of seizures experienced in the past year. Although there was no difference between the groups with respect to generalized seizures, more patients with a seizure emergency plan reported having both generalized and partial seizures (Table 2). Those with a seizure emergency plan were significantly more likely to have experienced 10 or more seizures in the past year ($P < 0.05$) and were more likely to report being on more than one epilepsy-related medication (Table 2). They were also significantly less likely to indicate their seizure frequency had decreased as a result of their current AED regimen ($P < 0.05$) (Table 2).

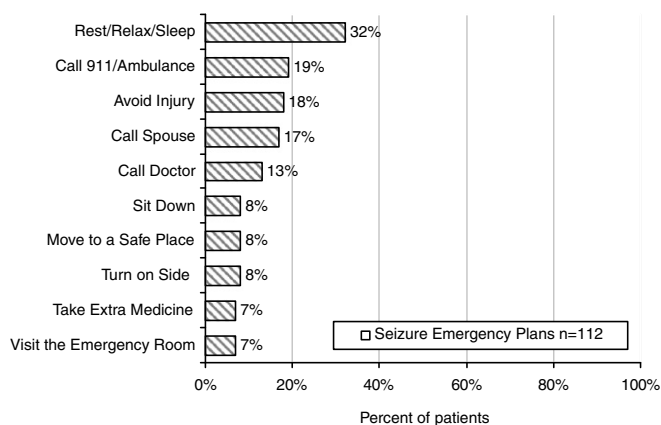
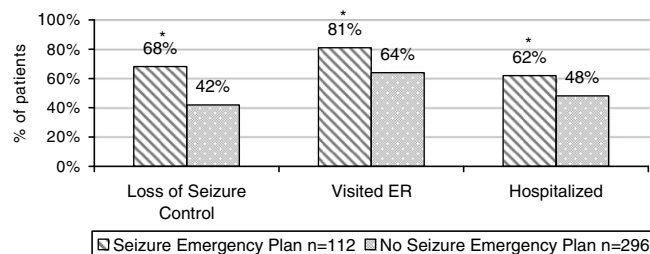


Fig. 1. Components of patient seizure emergency plans.



* denotes significance at $p < 0.05$.

Fig. 2. Experience of those with and without a seizure emergency plan.

Patients with a seizure emergency plan were significantly more likely to indicate that they missed a dose of medication prior to the onset of a seizure compared with those without a plan ($P < 0.05$) (Table 2). Following a seizure, patients with a seizure emergency plan were significantly more likely to take an extra dose of medication (41% vs 17%, $P < 0.05$) or take a rescue medication (13% vs 6%, $P < 0.05$).

In addition, patients with a seizure emergency plan (68%) were significantly more likely than those without a plan (42%) to report that they had experienced a loss of seizure control defined as “an unexpected increase in how bad a seizure is or how many seizures you have” ($P < 0.05$) (see Fig. 2). Patients with seizure emergency plans were significantly more likely to have ever visited the emergency room or been hospitalized as a result of a seizure ($P < 0.05$) (see Fig. 2).

3.4. Quality of life and productivity

Fig. 3 describes patients’ quality of life and productivity by seizure emergency plan status. Eighty-eight percent of patients with a seizure plan and 64% of those with no plan have ever had to miss or stop going to work or school due to a seizure ($P < 0.05$). Patients with a seizure emergency plan were significantly more likely than patients without a plan ($P < 0.05$) to report that they had to miss or stop going to school or work because of the following physical consequences of their condition: fatigue or tiredness, loss of driving ability, and injury incurred during a seizure. In addition to missing work, those with a seizure emergency plan were significantly more likely ($P < 0.05$) to have sustained an injury, fall, or accident or experienced ictal incontinence.

Patients were also evaluated on emotional functioning. Those with seizure emergency plans were significantly more likely ($P < 0.05$) than those without to report having experienced the following negative emotions as a result of a seizure: fear of having another seizure, embarrassment, and increased anxiety (Fig. 3). Furthermore, compared with patients without seizure emergency plans (27%), those with seizure emergency plans (43%) were significantly more likely to report experiencing increased family stress as a result of having a seizure ($P < 0.05$). Patients with a seizure emergency plan (23%) were also significantly more likely than patients without a seizure emergency plan (10%) to report that depression associated with a recent seizure interfered with their ability to go to work or school ($P < 0.05$).

Moreover, patients with seizure emergency plans were two times more likely than patients without such plans to say that they had to miss or stop going to school or work because of thinking or memory issues brought on by a seizure ($P < 0.05$). Other limitations in typical activity as a direct result of a seizure that were significantly more likely to be reported ($P < 0.05$) by those with seizure emergency plans included: missing a social event, losing or being fired from a job, and missing a deadline at work (Fig. 3).

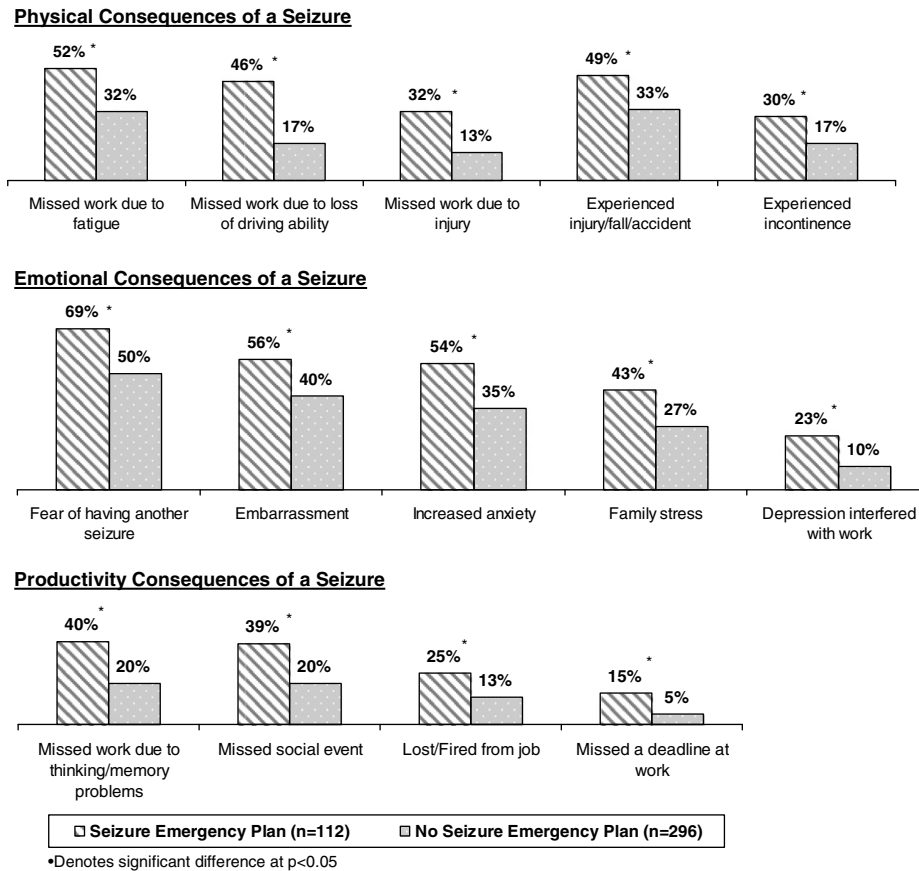


Fig. 3. Quality of life and productivity.

3.5. Physician and spouse involvement

Patients who have a seizure emergency plan were significantly more likely than those without to “strongly agree” or “agree” that they feel comfortable telling their doctor when they missed medications (75% vs 62%, $P < 0.05$). Half of patients with a seizure emergency plan and 32% of those without a plan reported that they “strongly agree” or “agree” that their doctor spends a lot of time talking to them about their epilepsy or seizure disorder and treatment ($P < 0.05$). In addition, patients who have a seizure emergency plan were significantly more likely than those without a plan to report that their partner/spouse is involved in the responsibility for making sure they take their epilepsy medication as prescribed (25% vs 14%, $P < 0.05$).

4. Discussion

Our study found that only 30% of adult patients with epilepsy reported having a seizure emergency plan, and those with plans demonstrated greater severity in their epilepsy as seen in their impaired seizure control, quality of life, and productivity. Findings from our study seem to indicate that patients with more severe epilepsy are targeted for the implementation of seizure emergency plans. However, seizure emergency plans should not only be reserved for those patients with more severe epilepsy, but rather should be considered a standard protocol for all patients with epilepsy. As seen in our study, at least one-third of patients who have no seizure emergency plan have experienced the following as a result of a seizure: fear of having additional seizures, embarrassment, feeling helpless, increased anxiety, or an injury/fall/accident. Sixty-four percent of those with no plan have ever had to miss/stop going

to school/work because of a seizure. These emotional stresses can be reduced by having a plan in place, which the patient and potential caregiver understand, when a seizure emergency occurs [6,9,12].

An analysis of the specific elements included in seizure emergency plans revealed a range of steps to be taken following a seizure including: resting/relaxing/sleeping, contacting emergency services, avoiding injury, laying the patient on his or her side during a seizure, and contacting a spouse or physician. The broad spectrum of seizure emergency plan components suggests there is no standard plan being used across physician practices. Although it is ideal to design a seizure emergency plan with each patient's unique condition and lifestyle in mind [8,11], it is unclear whether physicians are using a standard template in their practice or are personalizing plans.

Seizure emergency plans and, more specifically, the use of at-home therapies have also been shown to provide a sense of empowerment and control for patients, their family, and caregivers [11,12]. Seizure emergency plans aid patients and family members in improving or minimally affecting social opportunities as well as work- or school-related tasks or activities, and providing a means of control over the occurrence of unpredictable seizures. With effective implementation, patients may feel empowered not to limit activities or avoid social or work opportunities due to fear of having a seizure [7,11,12].

Our results revealed high self-reported adherence to seizure emergency plans (i.e., nearly three in four patients reported that they “always follow their seizure plan”). However, this is still an area in need of improvement given that approximately one in four patients with seizure emergency plans said that they “sometimes” follow their plan. Our findings also show that patients with seizure

emergency plans, when compared with those without plans, seem to be more engaged in their relationship with their physicians, and are able to communicate on issues related to their disease. Physicians must stress the need for all individuals—the patient, medical team, caregivers, and family members—to work together to ensure high adherence to and success of the seizure emergency plan. Without this type of cooperation and encouragement, the effectiveness of the seizure emergency plan will likely suffer.

4.1. Limitations

Given this study is one of the first to assess seizure emergency plan use in a large-scale survey, there are limitations. Our data were drawn from patients self-reporting their use of and experiences with a seizure emergency plan, condition-specific information, and medication-taking behavior. Relying on self-reported data alone may lead to imprecise reporting [16], and the scope of this study did not allow for verification of the self-reported information. Future parallel research with physicians could serve as a verification of study findings.

Patients in this study self-reported being diagnosed with epilepsy; however, members in the Harris Interactive panel undergo no clinical screening to confirm their self-reported diagnosis. Given that the survey required 20 min to complete and the monetary gain for participating was minimal (i.e., patients received points to accumulate toward a gift), it is unlikely that someone outside of the target classification would have participated.

Using an online panel as a source for recruitment may have introduced some selection bias. Patients who have volunteered to participate in an online panel may differ from those who are not online on attitudinal, behavioral, and demographic dimensions. We know from prior research that those individuals who are online frequently are more educated and are ethnically skewed [17]. To minimize these potential biases, we used propensity score weighting [15], which limits the potential for independent effects of confounding factors.

5. Conclusions

Our research demonstrates that the application of seizure emergency plans may be suboptimal and targeted more toward patients with severe disease in a real world setting. On the basis of this study, seizure emergency plans may need to be incorporated more fully into clinical practice and disease management for all patients with epilepsy regardless of severity. Future conduct of longitudinal

observational studies measuring the time since development of the seizure emergency plan is necessary to further understand the utilization and benefits of seizure emergency plans, as well as the association of the presence of seizure emergency plans with improved patient outcomes.

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