

# Evaluation of a Seizure Action Plan in an Adult Epilepsy Center

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## Abstract

### Background

Seizure action plans (SAPs) provide valuable information for patients to manage seizure emergencies, but are underutilized in adult epilepsy centers. The purpose of this project was to implement a structured SAP for adult patients with epilepsy.

### Methods

A pre/postimplementation design was used. Provider SAP utilization rates were analyzed over a 16-week period. A pre and postimplementation survey assessed participant perceived impact of the SAP on knowledge and comfort associated with managing seizure emergencies. Provider barriers and facilitators were also assessed.

### Results

Average provider SAP utilization rate was 51.45%. A total of 204 participants completed the surveys, which showed a significant increase in knowledge and comfort for all items,  $p < 0.001$ . At postsurvey analysis, 98% of participants felt that all patients with epilepsy should have a SAP regardless of seizure burden.

### Discussion

Implementing a structured SAP increased provider utilization and patient and care partner knowledge and comfort of managing seizure emergencies.

## Introduction

### Problem Description

Epilepsy is a common neurologic condition affecting 3 million adults in the United States.<sup>1</sup> Thirty to 56% of patients with epilepsy continue to have uncontrolled seizures despite conventional therapy with antiseizure medication.<sup>1,2</sup> Uncontrolled seizures and clusters of seizures contribute to the burden of epilepsy including increased emergency department visits, hospitalizations, and time away from work.<sup>3</sup> The estimated annual health care cost for epilepsy care is \$62 billion compared with \$14 billion for the general population.<sup>4</sup> Uncontrolled seizures are also associated with increased morbidity and mortality including sudden unexpected death in patients with epilepsy and status epilepticus.<sup>5,6</sup> Delayed treatment leads to reduced response to medical therapies, longer seizure duration, increased risk of brain injury, and increased hospital-associated mortality.<sup>7</sup> Standardized education may help people with epilepsy manage seizure emergencies. However, at an outpatient neurology clinic in the Midwest, standardized education was not available.

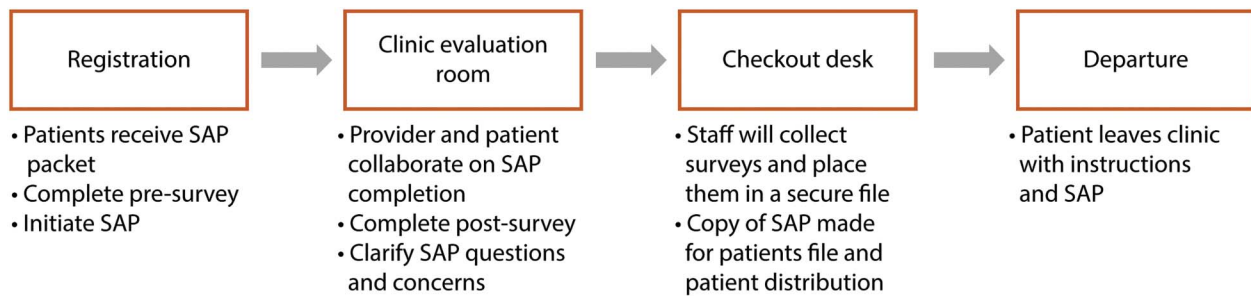
### Available Knowledge

The correlation between structured patient education and improved outcomes in patients with epilepsy is well established.<sup>8-12</sup> Educational interventions in patients with epilepsy leads to increased knowledge, better medication adherence, improvements in mood, decreased seizure frequency, and improvements in comfort associated with self-management.

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**Figure 1** Implementation Flowchart



Most seizures occur outside of the hospital setting. Most patients fear that they could have a seizure at any time yet do not have a response plan to address related concerns.<sup>13</sup> This highlights the need for a standardized educational intervention for improved patient knowledge and comfort with managing seizure emergencies. Most education programs are expensive and require extended time commitments and resources, both of which are barriers for dissemination and sustainability. By contrast, seizure action plans (SAPs) are efficient, cost effective, structured education tools used to engage patients and caregivers to actively participate in managing their condition.<sup>14</sup> Investigators have evaluated the use of SAPs to improve knowledge and reduce health care utilization rates in the pediatric population.<sup>9,15</sup> Although health care utilization rates were not reduced, pediatric caregivers with SAPs were more knowledgeable and comfortable with managing epilepsy-related care. Neville et al.<sup>15</sup> implemented a quality improvement project assessing provider use of a standard SAP in an outpatient pediatric clinic. Provider use of SAPs improved from zero to 58.5% within 3 months of project implementation.<sup>15</sup>

Although SAPs are beneficial, they are not often used in adult clinical practice.<sup>14</sup> Although current literature focuses on pediatric patients, disseminating an easy-to-use, standardized SAP in adult epilepsy clinics may provide an efficient and cost-effective educational plan that can improve outcomes and be sustained in clinical practice. To date, this is the first project focused on evaluating the use of a standardized SAP in an adult outpatient tertiary epilepsy center.

### Specific Aims

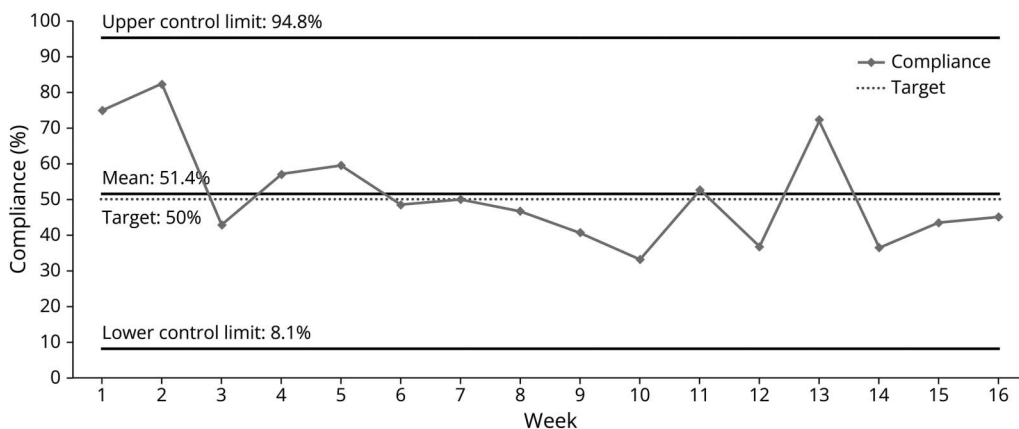
The purpose of this project was to implement a structured SAP for adult patients with epilepsy. The specific aims were to improve (1) provider SAP utilization rates and (2) epilepsy knowledge and comfort scores among adult patients with epilepsy and/or care partners before and after SAP implementation. Findings are reported using the SQUIRE 2.0 guidelines.<sup>16</sup>

## Methods

### Study Design, Context, and Sample

A preimplementation/postimplementation design was used. Five providers implemented the SAP (eAppendix 1) during

**Figure 2** Statistical Process Control Chart of Provider Utilization Rate of the Seizure Action Plan



**Table 1** Demographics and Clinical Characteristics

Variable	No. (%)
<b>Age, mean (SD)</b>	40.8 (14.72)
<b>Respondent type</b>	
Patient	142 (69.6)
Care partner	57 (27.9)
Other	2 (1.0)
Not reported	3 (1.5)
<b>Race</b>	
Black/African American	50 (24.5)
White	146 (71.6)
Hispanic	4 (2.0)
Asian	1 (0.5)
Other	1 (0.5)
Not reported	2 (1.0)
<b>Sex</b>	
Female	99 (48.5)
Male	101 (49.5)
Transgender	3 (1.5)
Not reported	1 (0.5)
<b>Lives alone</b>	41 (20.1)
<b>Highest education</b>	
High school	111 (54.4)
College	59 (28.9)
Postgraduate	12 (5.9)
Other	22 (10.8)
<b>Seizure status</b>	
Seizure free	86 (42.2)
1–2 mo	52 (25.5)
3–4 mo	31 (15.2)
5 or more months	30 (14.7)
Other	3 (1.5)
Unknown	2 (1.0)
<b>Tonic/clonic</b>	113 (55.4)
<b>Seizure of 5+ minutes</b>	61 (29.9)
<b>Two seizures within 24 h</b>	89 (43.6)

outpatient clinic visits at a Midwest outpatient tertiary epilepsy center (3 physicians and 2 advanced practice providers). Pretest and posttest knowledge and comfort were measured in patients with a confirmed history of epilepsy

and/or care partners aged 18 years or older. Care partners were invited to participate if the patient was unable to read, write, or comprehend English or per the patient's request (i.e., patient was unaware of seizure specifics). Patients with nonepileptic events, new to the clinic, and those seen by telehealth were excluded from participation.

### Practice Change, Tools, and Implementation

Before implementing the SAP, a brief PowerPoint presentation was provided summarizing project logistics to providers and registration staff. The SAP was previously developed by an expert panel and published for broad dissemination.<sup>14</sup> SAPs offer an opportunity to customize patient-specific information and includes provider contact information, seizure-related triggers, visualization and space to describe seizure semiology, and instructions for seizure first aid. How and when to use rescue therapy and seek emergency services were also included in the SAP. To enhance participant support, providers collaborated with patients and care partners to finalize and customize the SAP in the examination room. See Figure 1 for an implementation flow chart.

The knowledge and comfort survey was developed through a literature review and assessed for face validity by 5 epilepsy experts with experience ranging from 10 to 30 years. Before implementation, 5 patients reviewed the survey for readability and comprehension. The survey included 9 items and took less than 5 minutes to complete. Knowledge and comfort were assessed using a 4-point Likert scale (1 = strongly disagree to 4 = strongly agree). Participants completed the presurvey immediately before the clinic visit; the postsurvey was completed before departure. Provider barriers and facilitators were assessed monthly and when utilization rates were below target through a Qualtrics questionnaire and email. Reminders to complete the SAP were communicated verbally, by text messaging, division meetings, and email.

### Data Analysis

Provider SAP utilization rates were analyzed using descriptive statistics and a statistical process control chart. For knowledge and comfort scores, data were coded into categories of “yes” or “no” based on the Likert scale responses. Those who reported agree/strongly agree were coded as “yes,” and those reporting disagree/strongly disagree were coded as “no.” The percentage of those who answered “no” pre-SAP implementation was compared with the percentage who answered “yes” postimplementation using a McNemar test, as data were matched and binomial.

### Ethical Considerations

This innovative quality improvement project was formally evaluated using a quality improvement checklist and determined not to be human subjects' research. Participation in the project was voluntary, and patients could opt out at any time. Consent was implied by patients when they completed the pretest/posttest surveys.

**Table 2** Evaluation of Improvement for Pre- to Postimplementation for Knowledge and Comfort

Item	n reporting “no” at preimplementation	n (%) of those reporting “no” at preimplementation who reported “yes” at postimplementation	McNemar <i>p</i> value
I know how to recognize seizure emergencies	54	45 (83.3)	<0.001
I have been trained on what to do during a seizure	54	48 (88.9)	<0.001
My health care provider has educated me on situations that can trigger seizures	47	42 (89.4)	<0.001
I am comfortable recognizing seizure emergencies	49	45 (91.8)	<0.001
I am comfortable managing seizure emergencies	62	60 (96.8)	<0.001
All people with seizures should have a seizure action plan	24	22 (91.7)	<0.001
My health care provider has educated me on a seizure action plan and provided a copy of the plan	77	74 (96.1)	<0.001
My health care provider has discussed a seizure rescue medication that can be used for seizures when needed	57	52 (91.2)	<0.001
I have been educated on when to seek emergency services if needed for seizure emergencies	45	44 (97.8)	<0.001

## Results

### SAP Utilization

The average SAP utilization rate across the 16-week measurement period was 51.4% (Figure 2). The highest utilization rate occurred during week 2 (82.4%), and the lowest utilization occurred during week 10 (33.3%). No special cause variation was noted on the statistical process control chart. Key barriers of SAP utilization included the amount of time during a patient visit, forgetting to complete the SAP, and provider perception of SAP relevance. Facilitators included use of triage nurses and patient participation with SAP completion.

### Knowledge and Comfort Scores

A total of 204 participants completed both the preimplementation and postimplementation surveys. The participant demographics are displayed in Table 1. Most of the respondents were patients ( $n = 142$ , 69.6%) with care partners making up 27.9% ( $n = 57$ ) of project participants. The mean age was 40.8 (SD = 14.7) with a range from 19 to 81. The most common race was White ( $n = 146$ , 71.6%), and the gender distribution was similar with 48.5% ( $n = 99$ ) women.

Table 2 shows the percentage of knowledge and comfort that improved from preimplementation to postimplementation, which was indicated by a score of “no” at baseline and then a score of “yes” postimplementation. As shown, for all items, at least 83% of patients who reported “no” knowledge or

comfort at baseline improved postimplementation. Eighty-three percent of participants who initially responded “no” ( $n = 45/54$ ) perceived an improvement in the ability to recognize seizure emergencies, whereas 88.9% ( $n = 48/54$ ) and 89.4% ( $n = 42/47$ ) indicated that they were trained on what to do during a seizure and seizure-related triggers, respectively.

Ninety-seven percent of patients ( $n = 44/45$ ) who were unable to recognize when to seek emergency services at baseline reported the ability to do so after completing the SAP. Ninety-one percent ( $n = 45/49$ ) and 96.8% ( $n = 60/62$ ) of participants who were uncomfortable recognizing and managing seizures emergencies at baseline felt comfortable post-SAP education. Ninety-one percent ( $n = 52/57$ ) of participants who did not receive information on rescue therapy pre-SAP, received related discussions postimplementation. All knowledge and comfort items demonstrated statistically significant improvement,  $p = < 0.001$  (Table 2).

## Discussion

At this Midwest outpatient tertiary epilepsy center, there was an overall increase of SAP utilization for all providers. After reviewing literature with providers and addressing both patient and provider benefits, as well as offering materials to aid SAP discussions with patients, compliance of the distribution of SAP to patients increased by 51%.



In a survey study by Penovich et al.<sup>17</sup> the majority of patients and their caregivers felt that there was a moderate to major negative impact on quality of life secondary to seizure clusters.<sup>17</sup> The results suggested that patients were either overusing emergency department visits or underusing seizure rescue medications. Based on the current project, it is encouraging that simple discussions regarding the benefits of SAPs with providers could result in better counseling and initiation of a SAP, which may affect health care utilization.

More notable findings included statistically significant ( $p < 0.001$ ) improvement of knowledge and comfort scores for adult patients with epilepsy and/or care partners after SAP implementation. Specifically, patients felt more knowledgeable in recognizing seizure emergencies, knew what to do in case a seizure occurred, and knew when to call emergency services. Regarding comfort, patients felt more comfortable recognizing and managing seizures. Our work suggests that providing a SAP can improve patient and care partner knowledge and comfort for recognizing and treating seizure emergencies, which ultimately could lead to a decrease in prolonged seizures and avoidance of status epilepticus.<sup>13</sup> In addition, based on observational and survey studies, there could be a decrease in injuries and emergency department visits.<sup>18</sup> In a study by Penovich and associates,<sup>17</sup> 69% of patients felt that their work was negatively affected by seizure clusters, and 50% of those patients felt they needed to discontinue employment because of seizure-related clusters. Prevention of clusters through SAPs could potentially lead to decreased lapses of employment and improvements in mood and overall quality of life. Finally, most patients felt that all people with epilepsy or seizures should have a SAP, independent of patient seizure burden. This speaks to the importance of routinely integrating SAPs into clinic visits.

Regarding barriers, there were notable fluctuations of SAP utilization ranging from 82.4% (week 2) to 33.3% (week 10) suggesting that with the progression of weeks, the sustainability of a SAP might be of concern. To further support this, 100% ( $n = 5$ ) of providers felt that the biggest challenge to SAP implementation was limited time at a patient's visit which is consistent with a previous publication by Neville et al.<sup>15</sup> citing time and forgetfulness as major barriers to SAP administration. Interestingly, even when reducing the barrier of time (using a 1-page action plan, allowing patients and care partners to help with form completion and using triage nurses to assist with SAP completion), utilization varied between the weeks. Future efforts could focus on incorporating an electronic SAP, using process improvement models, and creating advance practice provider clinics focused on customizing SAPs. Finally, some providers cited that delivery of a SAP was not warranted for some patients because of a low burden of seizures or seizure freedom. Our project shows that patients want to be given a SAP regardless of seizure burden and thus distribution of this knowledge is imperative.

This project had several limitations, including a small number of participants and only providing SAP surveys to return patients that were seen in person. Excluding new patients was important as not all patients referred to the epilepsy center had a diagnosis of seizures and thus did not warrant a SAP. Future research could be directed to assessing patients' acceptance of a SAP during virtual visits and with newly diagnosed patients. This project evaluated knowledge and comfort scores immediately after the clinic visit. Future studies should evaluate knowledge and comfort score sustainability over the span of months and the correlation between SAPs and health care utilization.

It is beneficial to implement standardized SAP for adult patients with epilepsy. Our work suggests that simple discussions between providers and patients/care partners of how to manage seizure emergencies through use of a standardized SAP can increase knowledge and comfort about seizure emergencies. Finally, patients with epilepsy, regardless of seizure burden, feel that it is important to receive SAPs, making this an important topic to discuss during routine clinic visits.

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<b>Lucretia Long, DNP, MS, RN</b>	The Ohio State University Wexner Medical Center, Columbus	Drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; study concept or design; analysis or interpretation of data
<b>Staci S. Reynolds, PhD, RN, ACNS-BC, CPHQ, FAAN</b>	Duke University, Durham, NC	Drafting/revision of the manuscript for content, including medical writing for content; study concept or design; analysis or interpretation of data

Continued

## Appendix (continued)

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<b>Lisa S. Lewis, EdD, MSB, RN, CNE</b>	Duke University, Durham, NC	Drafting/revision of the manuscript for content, including medical writing for content; study concept or design; analysis or interpretation of data
<b>Michelle A. Webb, DNP, RN, BC-CHPCA</b>	Duke University, Durham, NC	Drafting/revision of the manuscript for content, including medical writing for content; analysis or interpretation of data
<b>Crystal Epley, APRN-CNP</b>	The Ohio State University Wexner Medical Center, Columbus	Drafting/revision of the manuscript for content, including medical writing for content; analysis or interpretation of data
<b>Sarita Maturu, DO</b>	The Ohio State University Wexner Medical Center, Columbus	Drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; study concept or design; analysis or interpretation of data

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