

# Epilepsy Treatment Complacency in Patients, Caregivers, and Health Care Professionals

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## Abstract

### Objective

To explore the perspectives of adult patients with epilepsy, caregivers, and health care professionals (HCPs) on treatment for seizures and treatment decisions, we developed and administered the STEP Survey (Seize the Truth of Epilepsy Perceptions).

### Methods

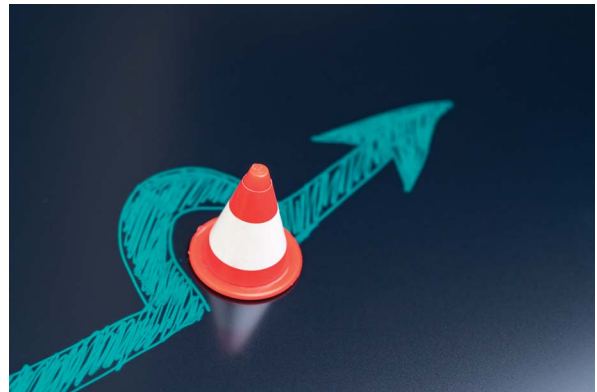
Participants were recruited from online panel M3 and by Rare Patient Voice and completed the self-administered online STEP Survey. Analysis of variance and chi-square tests were used for group comparisons.

### Results

The STEP Survey was completed by 400 adult patients, 201 caregivers, and 258 HCPs. Patients estimated reporting 45% of their seizures to their HCP, whereas caregivers estimated 83% and HCPs estimated 73% were reported. The most common reason for not reporting seizures was that the seizures were not serious enough to mention (patients 57%; caregivers 66%). A minority of patients (25%) and caregivers (30%) were very or extremely likely to ask their HCP about changing antiseizure medication (ASM) in the next 12 months. The HCP was most frequently selected by patients, caregivers, and HCPs as the person who initiates discussion of changing ASMs (patients 73%/caregivers 66%/HCPs 75%) and increasing ASM dosage (patients 77%/caregivers 68%/HCPs 81%). A majority of patients (65%) and caregivers (68%) somewhat or strongly agreed that they do not change ASMs due to fear of getting worse. HCPs perceive this fear less often, stating that 50% of their patients feel afraid when a second ASM was added.

### Conclusions

Improved reporting of all seizures, discussion of treatment changes, and the impact of fear on treatment decisions provide opportunities to reduce complacency and optimize patient outcomes.



Seizure freedom with minimal adverse effects is the ideal goal of epilepsy treatment,<sup>1-3</sup> yet approximately 40% of patients do not achieve 1-year seizure freedom despite treatment with 2

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antiseizure medications (ASMs) and 56% of patients treated with ASMs do not achieve seizure freedom in the preceding year.<sup>4,5</sup> The physical, social, and emotional consequences of uncontrolled seizures compared with seizure freedom are substantial and may include cognitive decline, reduced quality of life (QOL), higher risk of mood disorders, greater stigma, and increased risk of premature death.<sup>6-9</sup>

The STEP Survey (Seize the Truth of Epilepsy Perceptions) was developed to examine patient, caregiver, and health care professional (HCP) perspectives on seizures, treatment experiences, treatment satisfaction, pathways to treatment changes, and the effect of epilepsy and its treatment on the day-to-day lives and emotions of patients and caregivers. In this report, we examine treatment complacency and factors that may underlie treatment decisions in adults living with epilepsy, caregivers, and HCPs.

## Methods

### Study Design

The self-administered, online STEP Survey was developed by SK Life Science, Inc., and this cross-sectional study was conducted by Kantar Health in 2019. The survey was written at a 7th-grade reading level and included input from patients, HCPs, and the Epilepsy Foundation. The survey incorporated several quality checks to verify all logic, ranges, termination points, and open-ended questions and required approximately 40 minutes (patients and caregivers) to 45 minutes (HCPs) to complete. The STEP Survey questions addressed (1) epilepsy disease experience; (2) seizure freedom, seizure control, and seizure reduction; (3) treatment experience and goals; (4) life challenges in managing epilepsy; (5) the HCP/patient experience; (6) communication among patients, caregivers, and HCPs; (7) types and sources of epilepsy information; and (8) support networks.

### Participants

Adult patients with epilepsy, caregivers of patients with epilepsy, and HCPs who treat patients with epilepsy were recruited from online panel M3 and by Rare Patient Voice. Online panel M3 is an opt-in panel, meaning that people who joined the panel decided to participate regularly in surveys. An invitation to participate in the study was sent to panel members by email with a link to the survey. Patients with epilepsy also were recruited by Rare Patient Voice, an organization that specializes in patient recruitment services for the pharmaceutical industry. Rare Patient Voice uses an opt-in database and recruits patients through connections with support groups. An invitational email with a link to the survey was sent to identified patients.

Eligible participants lived in the United States and understood English, the language used in the survey. Eligible patients were aged  $\geq 18$  years, diagnosed with epilepsy (generalized, focal, or unknown), and currently on one or more ASMs. They were currently under the care of a general neurologist, epileptologist, or nurse practitioner (NP)/physician assistant (PA) at a

neurology practice or a primary care physician. Eligible caregivers were aged  $\geq 18$  years and were providing care for a person of any age with epilepsy who met the study patient eligibility criteria. Eligible caregiving (only 1 type needed) included reminding the patient to take medicine, attending epilepsy doctor appointments, knowing what to do during a seizure, talking to epilepsy doctors, picking up epilepsy medications, cooking or cleaning for the patient, driving the patient, helping the patient keep to a schedule, and keeping the environment safe from possible seizures.

Eligible HCPs included general neurologists (hereafter neurologists), epileptologists, and NPs/PAs. Eligibility criteria for neurologists and epileptologists included in practice 2–30 years and either board certification or eligibility in neurology. Neurologists and epileptologists had to spend  $\geq 70\%$  of their professional time treating patients,  $>50\%$  of whom were adults, including treating  $\geq 20$  adult patients with epilepsy in a typical month and treating  $\geq 15$  adult patients with focal seizures in a typical month. Eligible NPs/PAs worked in an office with a neurologist or epileptologist, were in practice 2–30 years, and spent  $\geq 70\%$  of their professional time treating patients. NPs/PAs had to work in practices with  $>50\%$  adult patients,  $\geq 20$  adult patients with epilepsy treated in a typical month, and  $\geq 5$  adult patients with focal seizures treated in a typical month.

The patient, caregiver, and HCP groups were independent of one another and were not a matched set. Participants received compensation: \$25 for M3 panel participants, \$70 for patients from Rare Patient Voice, and \$72 for HCPs, based on assessed fair market value for HCP survey response time.

### Standard Protocol Approvals, Registrations, and Patient Consents

The STEP Survey was deemed IRB exempt (Sterling IRB, Atlanta, GA). All potential respondents provided online informed consent before screening for eligibility and beginning the survey.

### Data Analysis

Consistency checks, quality control, and validation processes confirmed data quality. A total of 850 participants were planned, including 400 patients, 200 neurologists (approximately 75 epileptologists), 50 NP/PAs, and 200 caregivers. Means, SDs, and analysis of variance were used with continuous variables. Percentages, frequencies, and  $\chi^2$  tests were used with categorical variables. The number of assessed respondents was reported when missing data occurred.

### Data Availability

The data are available by request from the authors or from SK Life Science, Inc.

## Results

Four hundred adult patients with epilepsy, 201 caregivers, and 258 HCPs, including 112 neurologists, 96 epileptologists, and

50 NPs/PAs, completed the online STEP Survey. The mean age of patients was 40.2 years, of caregivers was 40.5 years, and of HCPs was 44.9 years. Patients had a mean epilepsy duration of 16 years, and caregivers had a mean caregiving duration of 10.7 years. Among patients and caregivers, 76% were women, and 67% of the HCPs were men. Patient-reported epilepsy type included generalized (41%), focal (41%), unknown origin (16%), do not remember (5%), and other (1.5%). Patients primarily received treatment from neurologists (78%), epileptologists (16%), NPs/PAs (4%), and primary care physicians (3%). At least 1 seizure with impaired awareness in the past year was reported by 61% of patients. Half (52%) of patients reported 1–9 seizures in the past year, 15% reported 10–20 seizures, 16% reported >20 seizures, and 17% reported zero seizures in the past year. More than half of patients (58%) were on their third or more ASM regimen, 25% were on their second ASM regimen, and 17% were on their first ASM.

Caregivers were a partner (23%), a parent (25%), an adult child (13%), another type of family member (27%), or a friend (11%) of the person with epilepsy. They lived in the same home as the person with epilepsy (66%), in the same neighborhood but not the same home (16%), in the same town but not the same neighborhood (5%), in a nearby town (10%), and in another town at least an hour away (3%).

Among neurologists, epileptologists, and NPs/PAs, the mean years in practice were 14.7, 11.8, and 8.7 years, and the average percentage of patients with focal seizures was 67%, 66%, and 55%, respectively. Patients treated by the neurologists, epileptologists, and NPs/PAs were on their first (49%, 40%, and 45%, respectively), second (31%, 32%, and 33%, respectively), or third or more (18%, 23%, and 19%, respectively) ASM or were not on an ASM (2%, 5%, and 3%, respectively).

## Report of Seizures

Patients, caregivers, and HCPs differed in their estimates of the percentage of seizures patients report to their HCP. Patients estimated reporting 45% of their seizures, whereas caregivers estimated 83%. HCPs estimated that patients report 73% of their seizures, and half of the HCPs somewhat (36%) or strongly (17%) agreed that their patients report every seizure. The most common reason given by patients and caregivers for why seizures were not reported is that the seizures were not serious enough to mention (patients 57%; caregivers 66%), followed by forgetting to mention the seizures (patients 33%; caregivers 43%) (figure 1).

## Treatment Discussions

A minority of patients (25%) and caregivers (30%) reported that they were very/extremely likely to ask their HCP about changing treatment in the next 12 months, including adding another ASM (patients 21%; caregivers 29%), increasing ASM dosage (patients 19%; caregivers 29%), or decreasing ASM dosage (patients 16%; caregivers 23%) (figure 2).

Patients, caregivers, and HCPs were asked to select who initiates discussions about changing ASMs and about increasing ASM dosage. There was agreement that the HCP is the person who initiates treatment discussions. A high percentage of patients (73%), caregivers (66%), and HCPs (75%; neurologists and epileptologists > NP/PAs,  $p < 0.05$ ) selected HCP as the person who initiates discussion about changing ASMs. Similarly, a high percentage of patients (77%), caregivers (68%; caregivers < patients and HCPs,  $p < 0.05$ ), and HCPs (81%) selected HCP for initiating discussion about increasing ASM dosage. There was divergence in perspectives on whether the patient and caregiver initiate ASM discussions. More patients (39%) selected patient as initiating discussion about changing ASMs compared with caregivers (28%) and HCPs (9%;  $p < 0.05$ ). Fewer HCPs (1%) selected patient as initiating discussion about increasing ASM dosage compared with patients (27%) and caregivers (24%,  $p < 0.05$ ). More caregivers (35%) selected caregiver as initiating discussion about changing ASMs compared with patients (11%) and HCPs (2%,  $p < 0.05$ ), and more patients than HCPs selected caregiver ( $p < 0.05$ ). More caregivers (29%) also selected caregiver as initiating discussion about increasing ASM dosage compared with patients (9%) and HCPs (2%,  $p < 0.05$ ).

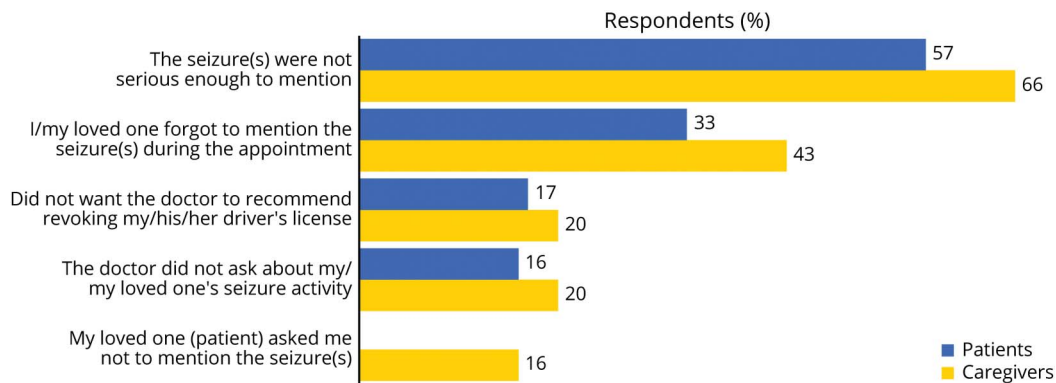
Half of patients (54%) and 42% of caregivers ( $p < 0.05$ ) reported no discussion of surgical treatment for epilepsy with their HCP (figure 3). Among those who discussed surgery, vagus nerve stimulation (patients 34%; caregivers 40%) and responsive neurostimulation (patients 17%; caregivers 24%,  $p < 0.05$  vs patients) were most frequently discussed. The survey was conducted before the US Food and Drug Administration's approval of deep brain stimulation for epilepsy. HCPs most often reported discussion of vagus nerve stimulation (21%), cortical resection (11%), and responsive neurostimulation (10%) (figure 3).

## Epilepsy Specialist Referral

Among patients with more than 1 seizure in the preceding 12 months, 18% of patients and 17% of caregivers reported referral to an epilepsy center, and 21% of patients and 24% of caregivers reported referral to another epilepsy specialist. Of the patients with  $\geq 13$  seizures per year, 27% reported referral to an epilepsy center. HCPs referred 14% of their patients to another epilepsy specialist and 16% to an epilepsy center. Among the HCPs who referred ( $n = 219$ ), the most common reasons included that the patient was a surgery candidate (82%), the patient was having significant breakthrough seizures on a third or more ASM regimen (73%; neurologists > epileptologists and NPs/PAs > neurologists and epileptologists;  $p < 0.05$ ), and the patient requested the referral (49%).

Patients, caregivers, and HCPs were asked how important it is that a patient treatment map be implemented that tells patients and caregivers to see an epileptologist or specialist as soon as they have symptoms and not wait for a longer time.

**Figure 1** Reasons Patients and Caregivers Did Not Report All Seizures to Health Care Professionals



Total n (patients + caregivers) = 151.

The majority of patients (61%), caregivers (68%), and HCPs (61%) agreed that such a treatment map is very/extremely important (figure 4).

### Fear of Seizures

Epilepsy-related fear was pervasive, as 39% of patients reported “epilepsy makes me always feel afraid.” Most patients (83%) and caregivers (94%) reported that they somewhat/strongly agree that they live in fear of another seizure, no matter how long it has been since the most recent seizure. Among HCPs, 78% reported somewhat/strongly agree that their patients will always be afraid that another seizure will come. A greater percentage of caregivers reported fear of another seizure compared with patients and HCPs ( $p < 0.05$ ).

Patients and caregivers reported being very/extremely afraid of having a seizure in diverse situations, with half or more of patients indicating while alone (50%), in a public place (53%), and while driving (57%) (figure 5). More than half of caregivers indicated being very/extremely afraid of their loved one having a seizure while in a public place (52%), asleep (56%), showering (57%), driving (61%), and while alone (77%). Almost half of patients (47%) and HCPs (48%) indicated that the patient’s worrying about having a seizure in a public place is very/extremely disruptive to their QOL. Among caregivers, 48% reported that worrying about their loved one having a seizure when they are not there is very/extremely disruptive to their QOL.

### Fear of Changing Treatment

When presented with the statement, “I do not want to change my/my loved one’s medications because I am afraid I/my loved one will get worse,” 65% of patients and 68% of caregivers somewhat/strongly agreed. Patients (11%) and caregivers (5%) who reported being not at all/not very satisfied with the patient’s HCP were asked what prevents the patient from switching HCPs. Half of these caregivers and 26% of these patients selected that I/my loved one is “afraid to lose all I/my loved one has worked for.”

When asked how likely they were to ask their HCP about changing treatments in the next 12 months, 52% of patients and 37% of caregivers reported not at all/not very likely. Among this group of patients and caregivers ( $n = 281$ ), 55% of patients and 59% of caregivers reported that they do not want to risk the progress they have made on medication by changing, and 41% of patients and 39% of caregivers reported that they do not want to risk having side effects on a new medication. When asked how they think their adult patients feel on each ASM treatment (i.e., select 5 of the 13 descriptors: trapped, hopeless, angry, depressed, supported, isolated, afraid, vulnerable, accepting, optimistic, relieved, overwhelmed, and other), 29% of HCPs selected afraid for the first ASM, which increased to half selecting afraid for the second (50%) and third (51%) ASMs.

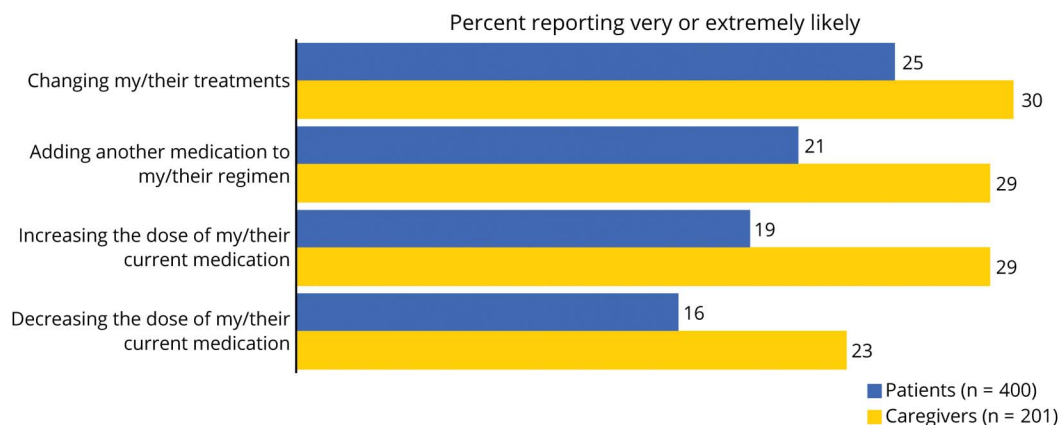
Among patients without a history of epilepsy surgery ( $n = 102$ ) and their caregivers ( $n = 63$ ), 42% of patients and 56% of caregivers selected “does not want to take the risk.” A greater percentage of caregivers (56%) vs patients (28%) reported that I/my loved one is afraid of epilepsy-related surgery ( $p < 0.05$ ).

## Discussion

Treatment complacency was common among patients, caregivers, and HCPs, despite uncontrolled seizures in many patients. STEP Survey responses point to several factors that may underlie treatment complacency. A key factor is that patients are reporting fewer than half of their seizures to their HCPs, whereas caregivers and HCPs estimated a higher percentage reported. This disconnect likely contributes to delays of discussions of treatment changes. A delay in HCP discussion initiation could have a meaningful effect on treatment complacency in that HCPs were selected as most likely to start treatment change discussions. To close the gap between seizures experienced and seizures reported to HCPs, the reasons patients provided for not reporting a seizure (i.e., not serious enough, forgetting, lose driver’s license, and HCP did not ask) should be addressed. Improved reporting of all seizure



**Figure 2** Likelihood of Asking Health Care Professionals About Treatment Changes in the Next 12 Months



occurrences and more frequent discussion of potential treatment changes, initiated by patients and caregivers as well as HCPs, may be needed to optimize treatment outcomes.

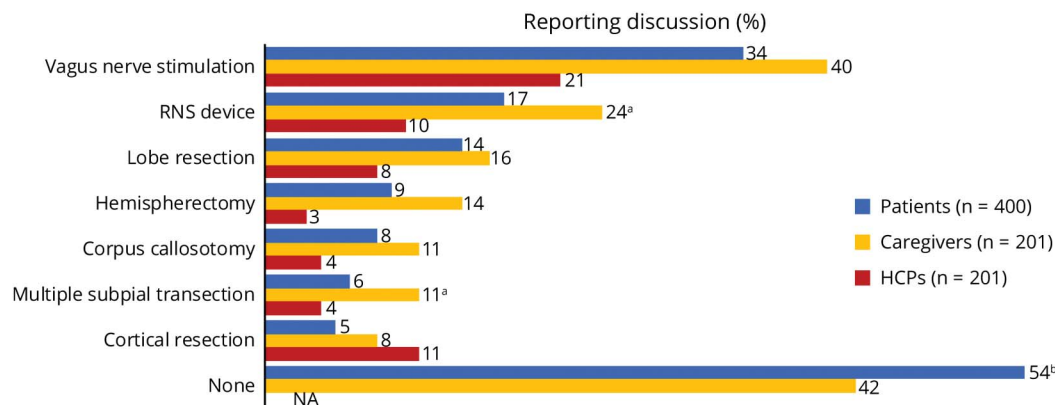
A second important factor for patients is fear that their seizures will worsen if they adjust their ASM regimen, and this may be an undisclosed reason for not reporting seizures. Fear of having another seizure pervades living with epilepsy for patients and caregivers and affects treatment decisions. Patients and caregivers were very/extremely afraid of seizures occurring within diverse settings (e.g., alone, public place, driving, showering, and sleeping), and worrying about having a seizure in a public place (patients) or when alone (caregivers) was very/extremely disruptive to QOL for approximately half of the patients and caregivers. These findings are consistent with patient-reported fear related to reactions of friends, family, and others, and fear of future episodes.<sup>10</sup>

Half of the patients were not at all/not very likely to ask their HCP about changing ASMs in the next year. Key fears that

may drive this decision include fear of deterioration in seizure control, reported by half of these patients, and fear of potential adverse effects of a new ASM, reported by 41% of these patients. HCPs are aware of patients' fear with an increased number of ASMs tried, recognizing that half of their adult patients feel afraid for the second and third ASM regimens. Because ASMs are the predominant management approach for epilepsy,<sup>11,12</sup> and all ASMs may be associated with adverse effects that can result in treatment discontinuation, nonadherence, or reduced QOL,<sup>11,13-15</sup> ongoing discussions about possible ASM changes and management of adverse effects are needed to allay patients' fears of changing treatment.

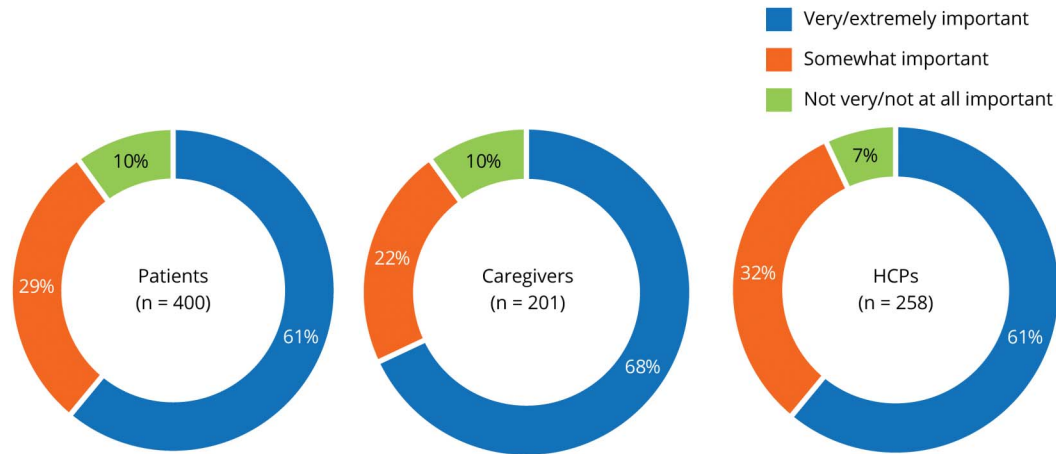
Fear of changing ASM treatment also was identified in the EPINEEDS study.<sup>16,17</sup> An anonymous survey evaluated the priorities of patients with epilepsy and their physicians within secondary and tertiary epilepsy centers in Italy. Approximately half of the patients (56.5%) had seizure remission for 1 year or longer. Despite overall satisfaction with

**Figure 3** Discussion of Surgeries for Epilepsy Among HCPs, Patients, and Caregivers



<sup>a</sup> $p < 0.05$  vs patients. <sup>b</sup> $p < 0.05$  vs caregivers. HCP = health care professionals; NA = not applicable; RNS = responsive neurostimulation.

**Figure 4** Patient, Caregiver, and HCP Perspectives on a Patient Treatment Map Telling Them to See an Epileptologist/ Specialist as Soon as They Have Symptoms



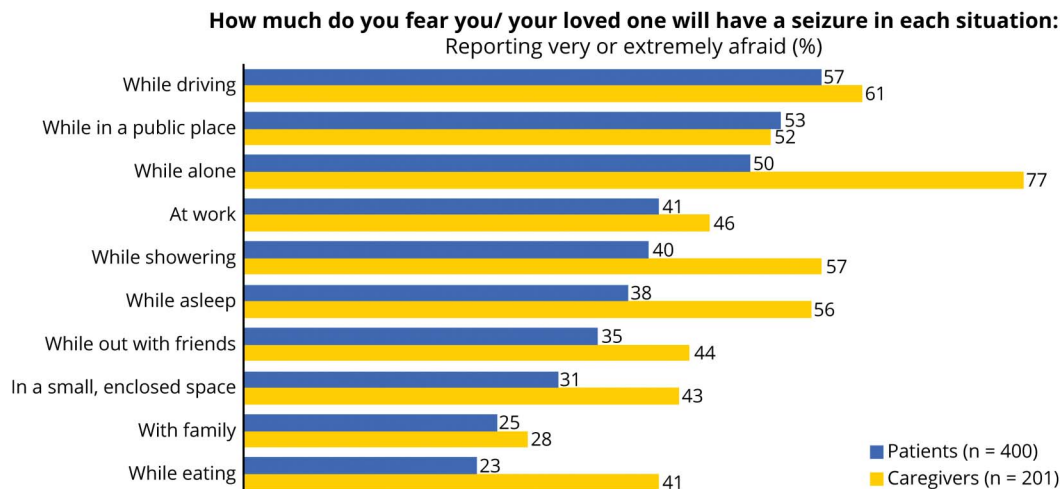
HCP = health care professional. Survey question: how important is it that the following program be implemented in the future: a patient treatment map that tells patients and caregivers to see an epileptologists/specialist as soon as they have symptoms, not wait for a long time. Percentages are the sum of respondents who selected the rating on a 5-point Likert scale ranging from 1 = not at all important to 5 = extremely important.

disease management for most patients, there were differences in priorities among patients and physicians, as seen in our study. A greater percentage of patients than physicians considered limitation of daily life activities, discovery of the cause of seizures, use of the right drug, and minimization of long-term side effects to be high priorities. These differences remained when grouped by patient prognostic categories (i.e., newly diagnosed, seizure remission, recurrent seizures, and drug-resistant seizures).<sup>17</sup> Both patients and physicians reported fear of short-term and long-term side effects for new ASMs.<sup>16,17</sup>

Implementation of a patient treatment map that tells patients to see an epileptologist or epilepsy specialist health care

provider as soon as they have symptoms was very/extremely important to the majority of respondents. Such a treatment map may help to reduce treatment complacency by encouraging earlier referral to a/another specialist or an epilepsy center for further evaluation of diagnosis, advanced medication options, or possible surgical evaluation. Specialist or epilepsy center referrals were not common among the STEP Survey respondents, consistent with infrequent and long-delayed referrals to epilepsy centers in patients with medication-resistant epilepsy<sup>18-21</sup> despite the American Academy of Neurology Quality Measures standard of care of referral of patients with treatment-resistant epilepsy to an epilepsy center every 2 years.<sup>22</sup> The discussion of epilepsy treatment options involving surgery was limited, and patients and caregivers identified patient fear as a reason for not

**Figure 5** Patients and Caregivers Report of Fear of Having a Seizure in Diverse Situations



Percentages are the sum of respondents who reported very or extremely afraid on a 5-point Likert scale ranging from 1 = not at all afraid to 5 = extremely afraid.

## TAKE-HOME POINTS

- The STEP Survey revealed complacency of patients and caregivers toward making changes in treatment.
- Patients report fewer of their seizures than either caregivers or HCPs believe they report.
- A minority of patients and caregivers initiate discussion of treatment changes with their HCP.
- A majority of patients and caregivers do not change treatment due to fear of their seizures getting worse.
- HCPs have an opportunity to reduce the impact of fear on treatment decisions and improve patient QOL.

evaluating this treatment option. HCP-initiated discussion of potential fear of starting a new medication or epilepsy-related surgical intervention may allow patients with seizures suitable for these options to consider these treatment changes earlier.

A potential limitation in using the STEP Survey results to widely inform clinical practice is that the surveyed patients with epilepsy may be more treatment-resistant than the general epilepsy population, with a regimen of 3 or more ASMs reported by more than half of the patients. Also, the STEP Survey patients, caregivers, and HCPs were not a matched set, and responses may have been affected by differences among the sampled populations (e.g., the patient respondents may be a more treatment-resistant population than the patients being treated by the HCP respondents).

In conclusion, evaluation of the perspectives of patients, caregivers, and HCPs confirmed that treatment complacency is common despite controlled seizures with many medication side effects or uncontrolled seizures. Potential strategies to mitigate treatment complacency and optimize treatment outcomes include improved reporting of all seizure occurrences and frequent discussion of and education about possible treatment changes. Although patients and caregivers experience pervasive fear and worry about seizures, this may not motivate patients with intolerable side effects or uncontrolled seizures to seek treatment changes due to fear of worsening seizures or side effects. Knowledge of these fears provides an opportunity for HCPs to provide broader care, potentially reduce the impact of fear on treatment decisions, and ultimately improve QOL.

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## Disclosure

P.E. Penovich is an advisor for Engage, LIVIS, Neurelis, and SK Life Science, Inc., and has been a speaker for GW Pharmaceuticals, Neurelis, SK Life Science, Inc., and UCB Pharma. J.M. Stern is a consultant for Eisai, Greenwich, LivaNova, SK Life Science, Inc., Sunovion, and UCB Pharma. D.A. Becker is an advisor for Neurelis, SK Life Science, Inc., and Supernus and has been a speaker for NeuroPace, Supernus, and SK Life Science, Inc. L. Long is an advisor for Eisai, Neurelis, SK Life Science, Inc., and Supernus and has been a speaker for LivaNova. N. Santilli is a consultant/advisor for Neurelis and SK Life Science, Inc. L. McGuire is an employee of MedVal Scientific Information Services, which was contracted by SK Life Science, Inc, for medical writing services. E.Y. Peck is an employee of Kantar Health, which provided consulting services to SK Life Science, Inc., for this study. Full disclosure form information provided by the authors is available with the full text of this article at [Neurology.org/cp](http://Neurology.org/cp).

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## Appendix Authors

Name	Location	Contribution
<b>Patricia E. Penovich, MD</b>	Minnesota Epilepsy Group, Saint Paul, MN	Interpreted the data; revised the manuscript for intellectual content; and approved the final version for submission.
<b>John M. Stern, MD</b>	University of California at Los Angeles	Interpreted the data; revised the manuscript for intellectual content; and approved the final version for submission.
<b>Danielle A. Becker, MD</b>	Penn Epilepsy Center, Hospital of the University of Pennsylvania, Philadelphia (affiliation at time work was done)	Interpreted the data; revised the manuscript for intellectual content; and approved the final version for submission.
<b>Lucretia Long, APRN-CNP</b>	The Ohio State University Medical Center, Columbus	Interpreted the data; revised the manuscript for intellectual content; and approved the final version for submission.
<b>Nancy Santilli, PNP, MN</b>	Human Care Systems, Inc., San Francisco, CA	Interpreted the data; revised the manuscript for intellectual content; and approved the final version for submission.

Continued

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## Appendix (continued)

Name	Location	Contribution
<b>Lynanne McGuire, PhD</b>	MedVal Scientific Information Services, Princeton, NJ	Wrote the initial manuscript draft based on input from the other authors and revised the manuscript for intellectual content under their guidance.
<b>Eugenia Y. Peck, PhD</b>	Kantar Health, New York, NY	Designed the survey; collected the data; performed the analysis; interpreted the data; revised the manuscript for intellectual content; and approved the final version for submission.

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## Epilepsy Treatment Complacency in Patients, Caregivers, and Health Care Professionals

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