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Burden of Seizure Clusters on Patients With Epilepsy and Caregivers

Survey of Patient, Caregiver, and Clinician Perspectives

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Objectives: To characterize the burden of seizure clusters (SC) on patients and caregivers, a large internet-based survey was conducted.

Methods: The Seizure Cluster Burden of Illness US Survey was conducted online by Harris Poll on behalf of The Epilepsy Foundation in September 2014. Respondents included adult patients 18 years and above with epilepsy or a seizure disorder who had experienced SC in the past year (defined as ≥ 2 seizures within 24 h outside the patient's typical seizure pattern), caregivers providing current care for a patient with SC (adult or child), and clinicians (neurologists, epileptologists) who treat adult or pediatric patients. Responses to a wide range of topics, including emotional well-being, daily function, productivity, and approach to clinical practice, were collected.

Results: There were 861 respondents (259 adult SC patients, 263 caregivers, and 339 clinicians). A majority of all respondent groups felt SC have a moderate/major negative impact on patient and caregiver quality of life, including emotional, financial, and social components. Responses indicated possible overutilization of emergency room services and underutilization of rescue treatment. Only 30% of patients reported having a seizure emergency plan. Some responses showed discrepancies between clinicians and patients/caregivers in the perceived degree of negative impact of SC and management practices for SC.

Conclusions: These results suggest the need for increased education on managing SC. Clinicians need to develop seizure emergency plans and discuss rescue therapies, whereas patients and caregivers need to ask for and utilize these management strategies.

Key Words: epilepsy, survey, seizure clusters, caregivers, quality of life

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Epilepsy, one of the most common neurological disorders, affects ~70 million people worldwide.[1] Among patients with epilepsy, ~30% have uncontrolled seizures despite treatment with antiepileptic drugs.[2] Therefore, drug-resistant epilepsy occurs among a wide range of patients with epilepsy, including pediatric and elderly individuals.[3–5] Some of these patients may experience bouts of increased seizure activity—also referred to as seizure clusters (SC), acute repetitive seizures, or serial, recurrent, or crescendo seizures.[6] Although it is generally understood that SC refer to multiple seizures within a short period of time and fall somewhere between a single seizure and status epilepticus, there is no standard definition regarding the number of seizures within a certain time period; therefore, SC prevalence rates vary considerably.[6] In a study conducted at a tertiary epilepsy center in patients with varying degrees of seizure control, the prevalence of SC was 20% to 30%.[3] Importantly, risk factors for SC not only include history of drug-resistance but also history of head trauma, catamenial epilepsy, or prior SC event.[3,5,7]

Despite lack of standardized nomenclature and definition, the epilepsy field generally considers SC a potential emergency that may benefit from treatment. Patients with SC are at risk for brain/neuronal damage, postictal psychosis (characterized by auditory and visual hallucinations, delusions, paranoia, affective change, and aggression), status epilepticus, and higher mortality relative to patients without clusters.[6,8–11] Untreated SC may result in greater resistance to future drug treatment and lead to patient injury or status epilepticus requiring emergency room (ER) and other health care utilization services.[12–14] The financial burden of untreated SC is high for patients/caregivers as well as their communities; indeed, direct costs of seizure management (including SC) in the ER ($554 to $17,126/patient) can be much greater relative to costs of available prescription abortive therapies (~$400/use).[15] Such negative consequences of SC, along with the sizeable patient population potentially at risk, justify greater investment in research efforts to better understand SC.

The negative impacts of epilepsy on patient quality of life (QOL) have been well documented, and the QOL consequences for caregivers have started receiving more attention[16,17]; however, few data are available on the impact that SC/repetitive seizures, specifically, have on QOL.[18] With limited literature documenting the impact of SC on patient/caregiver QOL, physician specialists who manage SC patients (ER clinicians, neurologists, and pediatric neurologists) may

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be unaware of the need to address such patient concerns. Therefore, a better understanding of the impact that SC have on patients/caregivers could provide insight into opportunities for enhanced SC management.

The Seizure Cluster Burden of Illness US Survey was conducted to assess the perceptions and practices of clinicians, caregivers, and patients on the SC experience and burden of illness. Here, we report an analysis of survey data for SC patient and caregiver QOL, including emotional well-being, functionality, and productivity, as well as SC management practices by over 850 clinicians, patients, and caregivers.

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METHODS

Study Design

The Seizure Cluster Burden of Illness US Survey was conducted online (September 2 to 30, 2014) by Harris Poll on behalf of The Epilepsy Foundation with unrestricted grant support from Upsher-Smith Laboratories Inc. The questionnaire was ~20 minutes in length, consisting primarily of closed-ended pick-list and grid questions. Queries assessed overall patient health, the impact of seizure disorder, and SC on QOL (emotional, social, work/school), and the care, management, and treatment of seizure disorders and SC. The operational definition for "SC" used in this survey was ≥2 seizures/24 hours outside a patient's typical seizure pattern. To assess eligibility, participants were asked "Have you/has your family member, friend, or loved one ever experienced 2 or more seizures within a 24-hour period that are outside your/their typical seizure pattern?" Only respondents who selected the option "Yes, within the past 12 months" could proceed to the remaining questions in the survey as qualified respondents (the other 3 options to answer the question were "Yes, more than 12 months ago," "No, I/they have never experienced 2 or more seizures within a 24-hour period that are outside my/their typical seizure pattern," and "Not sure/don't remember"). This operational definition of SC was based on adult and adolescent data for most common seizure types, namely partial with or without secondary generalization; the clause "outside your typical seizure pattern" was used to exclude patient conditions or circumstances where multiple seizures in a 24-hour period are a common occurrence.

In this survey, some numeric questions (eg, current age, age at diagnosis, number of days experienced at least 1 seizure in the past month, etc.) were asked as open-ends to more accurately calculate mean and median responses. Agreement questions allowed 1 of 4 responses: strongly disagree, somewhat disagree, somewhat agree, or strongly agree. Impact questions were asked in 2 different ways and allowed one of the following responses: (1) major impact, moderate impact, slight impact, or no impact, and (2) very positive impact, somewhat positive impact, no impact, somewhat negative impact, or very negative impact.

Questionnaire content overlapped by ~80% between patients and caregivers, and 50% between clinicians and patients/caregivers.

Respondents

Respondents were in 1 of 3 groups:

(1) Patients (18 y and above) with epilepsy or seizure disorder who had experienced SC in the past year.
(2) Caregivers currently providing care for a patient with SC [adult or child (0-17 y)] who is a friend, family member, or loved one (ie, unpaid, nonprofessional).
(3) Clinicians (neurologists and epileptologists) treating adult or pediatric patients.

Patient and caregiver respondents were recruited via Harris Poll Online panel (www.harrispollonline.com) and The Epilepsy Foundation (via www.epilepsy.com, Facebook, Twitter, and email newsletter). Clinicians were recruited via mail using a purchased address list of neurologists (American Medical Association).

Patients responded about their experiences. Caregivers responded regarding their patient's experiences and their own, and all caregiver results cited are based on the total sample of caregivers of adult or pediatric patients. Clinicians' responses reflected their opinions of the patient and caregiver experience. Caregivers, clinicians, and patients were recruited separately and not necessarily linked. Clinicians who completed the survey received a $65 honorarium. Patients and caregivers from the Harris Poll Online panel received points redeemable for various products, whereas those from The Epilepsy Foundation did not receive incentives.

Statistical Analysis

Raw data were weighted to accurately reflect the composition of US adults who experience SC, US adults who are caregivers of adult or pediatric SC patients, and US clinicians. Patient and caregiver results were weighted for age by sex, region, race/ethnicity, income, and education; clinician results were weighted for region, years in practice by sex, and primary medical specialty.

To be as representative as possible, raw data for all epilepsy patients and caregivers who entered the survey (regardless of whether they ultimately qualified for the study on the basis of experiencing SC) were weighted, where necessary, in order for the survey respondents to more accurately reflect the demographic profile of US adult epilepsy patients and epilepsy caregivers, as determined by internal Harris Poll screener results. Data from the subset of fully qualified respondents (ie, SC patients and caregivers) were then extracted from this larger group of epilepsy patients and caregivers, resulting in a more representative data set of SC patients and caregivers. This method of "drop out weighting" (or "drop weighting") keeps the benefits of representativeness and applies it to the group of interest. Drop out weighting is standard practice in situations with targets for the larger group sampled for the survey (eg, epilepsy patients) but not the narrower group defined in the qualifying criteria (eg, SC patients). As the larger group is sampled and weighted to be appropriately representative, the narrower group benefits from this higher-level representativeness and, in turn, is representative itself of its own corresponding population. The weighting algorithm for patients and caregivers also included a propensity score, which allowed adjustment for attitudinal and behavioral differences between those who are online versus those who are not, those who join online panels versus those who do not, and those who responded to this survey versus those who did not; propensity weighting was deemed unnecessary for clinician data as they were recruited via mail and the vast majority of US physicians are online or have internet access at least at their office.

The weighted base may vary slightly for individual items within a question due to the contingent nature of the survey (eg, questions were not asked of caregivers of younger patients for whom age would render the question inapplicable). Percentages were calculated using the weighted base, defined as the weighted number of total respondents. Statistical comparisons were determined by t test (95% confidence level). Because the sample is based on those who agreed to participate in the Harris Poll Online panel and/or are members of The Epilepsy Foundation, no estimates of theoretical sampling error can be calculated.

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RESULTS

Respondents

Of 861 respondents, 259 were adult SC patients, 263 were caregivers [of children (n = 103) or adults (n = 160)], and 339 were clinicians (neurologists, n = 178; epileptologists, n = 161) treating children (n = 139) or adults (n = 200). The majority of clinicians surveyed were male (n = 249) and had been in practice ≤10 years since completing residency (n = 195). Patient and caregiver demographics used to weight survey data are shown in Table 1.

Baseline seizure and SC frequency are shown in Table 2. Overall, patients had SC for an average (median) of 4 days in the past month and 30 days in the past year. Within the past month, approximately three-fourths of participants reported experiencing a seizure and just over half reported experiencing a SC (Table 2). A total 64% of all patients had a caregiver to help with their seizure disorder, and 88% of all caregivers reported their patient lived with them.

Impact of Seizure Disorder and SC on Patients

Seizure Disorder

As the result of a seizure disorder, the majority of patients (71%) and caregivers (61%) had lowered expectations of the daily living activities they are/their patient is able to do and agreed (somewhat/strongly) that the patient is prevented from living the life they want to live (78% and 81%, respectively). A similar percentage of patients (81%), caregivers (85%), and clinicians (86%) somewhat or strongly agreed that a seizure disorder prevents the patient from doing things other people can do. Examining these responses more closely, clinicians may underestimate perceived limitations relative to patients or caregivers, as nearly half of patients (47%) and caregivers (48%) strongly agreed versus only 23% of clinicians ($P < 0.05$ for both). A majority of patients, caregivers, and clinicians (72%, 62%, and 73%) said patients worry most about having more seizures. The majority of patients and clinicians also reported that patients worry most about losing independence (68% and 65%), inability to drive (64% and 83%), brain damage (64% and 51%), worsening condition (64% and 62%), being a burden (62% and 53%), and loss of seizure control in public (54% and 66%).

Significantly more clinicians versus patients or caregivers (82% vs. 75% and 62%; $P < 0.05$) and significantly more patients versus caregivers ($P < 0.05$) somewhat or strongly agreed that patients live in fear that they will have a seizure at any time; however, the percentage of patients reporting strong agreement was significantly higher than clinicians (41% vs. 24%; $P < 0.05$; caregivers, 31%). Similar findings were observed for whether patients were embarrassed to talk about their seizure disorder, with significantly more clinicians somewhat or strongly agreeing versus patients or caregivers (58% vs. 38% and 37%; $P < 0.05$), even though the percentage of patients and caregivers reporting strong agreement (17% and 13%) was significantly higher than clinicians (7%; $P < 0.05$). Significantly more patients versus clinicians agreed they do not have a social life as a result of seizures (61% vs. 48%; $P < 0.05$; caregivers, 49%).

QOL in Patients With SC

Similar to seizure disorders in general, clinicians may underestimate overall limitations from SC as described by patients and caregivers. Although a significantly higher

TABLE 1. Demographics of Patient and Caregiver Respondents (Unweighted)

	Patients (N = 259)	Caregivers (N = 263)
Sex [n (%)]		
Male	60 (23)	53 (20)
Female	199 (77)	210 (80)
Age (mean) (y)	41	45
Region [n (%)]		
East	52 (20)	71 (27)
Midwest	66 (25)	63 (24)
South	88 (34)	76 (29)
West	52 (20)	53 (20)
Non-US State	1 (0.4)	0
Ethnicity [n (%)]		
White	206 (80)	214 (81)
Hispanic	27 (10)	13 (4.9)
Black/African American	8 (3.1)	14 (5.3)
Asian/Pacific Islander	4 (1.5)	3 (1.1)
Native American/ Alaskan	4 (1.5)	2 (0.8)
Mixed race	1 (0.4)	3 (1.1)
Other	2 (0.8)	1 (0.4)
Declined to answer	7 (2.7)	13 (4.9)
Income [n (%)]		
<$15,000	49 (19)	9 (3.4)
$15,000-$49,999	100 (39)	78 (30)
$50,000-$99,999	49 (19)	88 (33)
≥$100,000	24 (9.3)	60 (23)
Decline to answer	37 (14)	28 (11)
Highest level of education [n (%)]		
≤High school	47 (18)	25 (10)
College	169 (65)	177 (67)
Graduate level	43 (17)	61 (23)

Percentages ≥10% have been rounded to the nearest whole number; therefore, the percentages within a category do not always sum to 100%.

TABLE 2. Baseline Seizure and Seizure Cluster Frequency (Weighted)

	Patients (N = 259)	Caregivers (N = 263)
Baseline seizure frequency		
Days with ≥1 seizure within the past month		
Median (d)	4	4
Mean (SD) (d)	7.3 (8.4)	9.4 (10.65)
Days with ≥1 seizure within the past 12 mo		
Median (d)	30	30
Mean (SD) (d)	70.1 (93.56)	97.0 (125.18)*
Last time with a seizure, % of respondents		
Within the past month	76	72
≥1 mo-<6 mo ago	16	20
6 mo-1 y ago	7	7
Baseline seizure cluster frequency		
Last time with a seizure cluster, % of respondents		
Within the past month	53	52
≥1 mo-<6 mo ago	36	30†
6 mo-1 y ago	11	18

The n values shown reflect the unweighted base, which may vary slightly for individual items due to the contingent nature of the survey. Percentages ≥10% have been rounded to the nearest whole number; therefore, the percentages within a category do not always sum to 100%.

*$P < 0.05$ versus patients.

†$P < 0.05$ versus patients for ≥1 month to <3 month (27% for patients vs. 16% for caregivers).

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percentage of clinicians than caregivers agreed (somewhat or strongly) that SC get in the way of the things patients need to do each day (74% vs. 63%; $P < 0.05$; patients 68%), a significantly higher percentage of patients (32%) and caregivers (21%) strongly agreed versus clinicians (14%; $P < 0.05$ for both). Significantly more clinicians (80%) relative to patients (70%) or caregivers (66%) felt that SC have a moderate/major negative impact on patient QOL ($P < 0.05$ for both). When discussing with patients how SC may affect their lives, most clinicians reported typically discussing ability to drive (73%), independence (59%), activities of daily life (51%), and job/ability to work (51%). A majority of patients and caregivers of children and adults felt SC negatively affect the patient's ability to drive, mood, job/ability to work, independence, ability to travel, extracurricular activities, and social activities/hobbies (Fig. 1). However, 52% of patients and 54% of caregivers felt patients with SC can achieve a fulfilling life, and 74% of clinicians felt a fulfilling life was possible (somewhat agree/strongly agree; $P < 0.05$ for both).

Work/Employment in Patients With SC

A total of 69% of patients reported that their job/career or ability to work has been somewhat/very negatively impacted by SC. Of these patients (n = 167), >60% have experienced a seizure at work, and over half have had to stop working for a period of time due to SC (Fig. 1 inset).

Emotional, Financial, and Social Burden in Patients With SC

A significantly higher percentage of clinicians versus patients or caregivers of children and adults somewhat agreed that SC cause significant emotional and financial burden, whereas a significantly higher percentage of patients strongly agreed versus clinicians (Table 3). A majority of patients reported that SC made them feel exhausted, confused/slow thinking, stressed, depressed, helpless, and/or scared (see Fig., Supplemental Digital Content 1, http://links.lww.com/NRL/A26). In all groups, a majority agreed that having SC has made patients' lives miserable (57% patients; 53% caregivers; 55% clinicians).

Impact of SC on Caregivers

Overall, 58% of caregivers reported a major/moderate negative impact of SC on their own QOL, with approximately half noting negative effects on overall mood, vacation, travel, hobbies/social activities, and their job (Fig. 2). A total of 48% of caregivers reported that their work has been somewhat/very negatively impacted by their patient's SC. Of these caregivers (n = 129), almost half noted they had to reduce work hours or take days off, and 43% had to stop working altogether for a period of time (Fig. 2 inset). When describing how they feel when their patient experiences SC, caregivers most commonly felt stressed (67%), helpless (64%), scared (59%), and/or overwhelmed (52%).

Management of Seizure Disorder and SC

Most patients and caregivers were generally satisfied with the care provided by clinicians, with 61% of patients and 70% of caregivers rating the care they generally receive from health care professionals as excellent or good. Most patients and caregivers believe their clinician is very knowledgeable about managing their seizure disorder (81%, 90%) and is doing everything possible to control it (81%, 84%). They typically agreed with the clinician about managing their seizures (76%, 87%) and were generally satisfied with how well their clinician explains things (75%, 82%).

Even so, the survey identified disparity in the perception of topics covered during visits, with significant differences between clinician and patient/caregiver responses for every topic queried and particularly large patient-clinician gaps for changes in nonseizure medication, injuries/ER visits, seizure impact on patient life, plans for late/missed doses, and diary entries (Fig. 3). Most patients (61%) and caregivers (66%) were familiar with the term "seizure clusters" before taking the survey, though only about one-third said their clinician had used that phrase to describe SC as defined in this survey. Among clinicians who use multiple terms (n = 328), "seizure cluster" was the most commonly used term (37%), but other terms such as "recurring seizures" (25%), "repetitive seizures" (12%), and "seizure flurries" (10%) were also used.

About half (51%) of clinicians reported that they encourage >75% of their patients to use a seizure diary; 55% of patients and 62% of caregivers reported using a seizure diary. About half (52%) of clinicians reported that a majority (51% to 100%) of their patients have a seizure emergency plan, though only 30% of patients reported having one in place.

When asked what they typically recommend for patients when a SC occurs, most clinicians said they advise taking a rescue medication (79%), calling the doctor's office (67%), and visiting the ER (61%; see Fig., Supplemental Digital Content 2, http://links.lww.com/NRL/A27). Top patient responses for what they do when a SC occurs were to stay calm (34%), do nothing (27%), visit the ER (24%), call the doctor (20%), and take rescue medication (20%; see Fig., Supplemental Digital Content 2, http://links.lww.com/NRL/A27). A total of 31% of patients and 40% of caregivers used an ER for SC in the past year, with 26% of patients reporting they would seek out ER care as their first option if experiencing a seizure disorder problem.

DISCUSSION

To our knowledge, this is the first large-scale survey to characterize burden of SC on patients and caregivers from the perspective of patients, caregivers, and clinicians. Questions in the survey were used to assess SC impact on daily living and QOL, and to gather information on seizure management and communication between clinicians and patients/caregivers. These findings describe how SC negatively impact patients and caregivers in a variety of ways in emotional, social, and financial realms. Survey results also provide insight into the types of actions patients and caregivers are taking when dealing with seizures and SC, and how these may differ from clinician recommendations. Interestingly, results highlight areas of disparate perceptions among patients, caregivers, and clinicians—both in the burden of SC and the management of seizures. Together, this information can be used to identify areas requiring more attention during physician-patient/caregiver interactions, which may improve patient/caregiver satisfaction and health care outcomes in the treatment of seizures and SC.

Many studies have characterized decreased patient QOL with epilepsy.[16,19–21] Further, even though caregiver burden in epilepsy is relatively less studied compared with other chronic neurological conditions,[16,17] a recent study using standardized scales reported similar magnitude of caregiver burden to that reported for other neurological conditions.[17] Although results summarized here did not utilize standardized scales, an overwhelming majority of patients and caregivers selected negative adjectives to describe their SC experience ("exhausted,"

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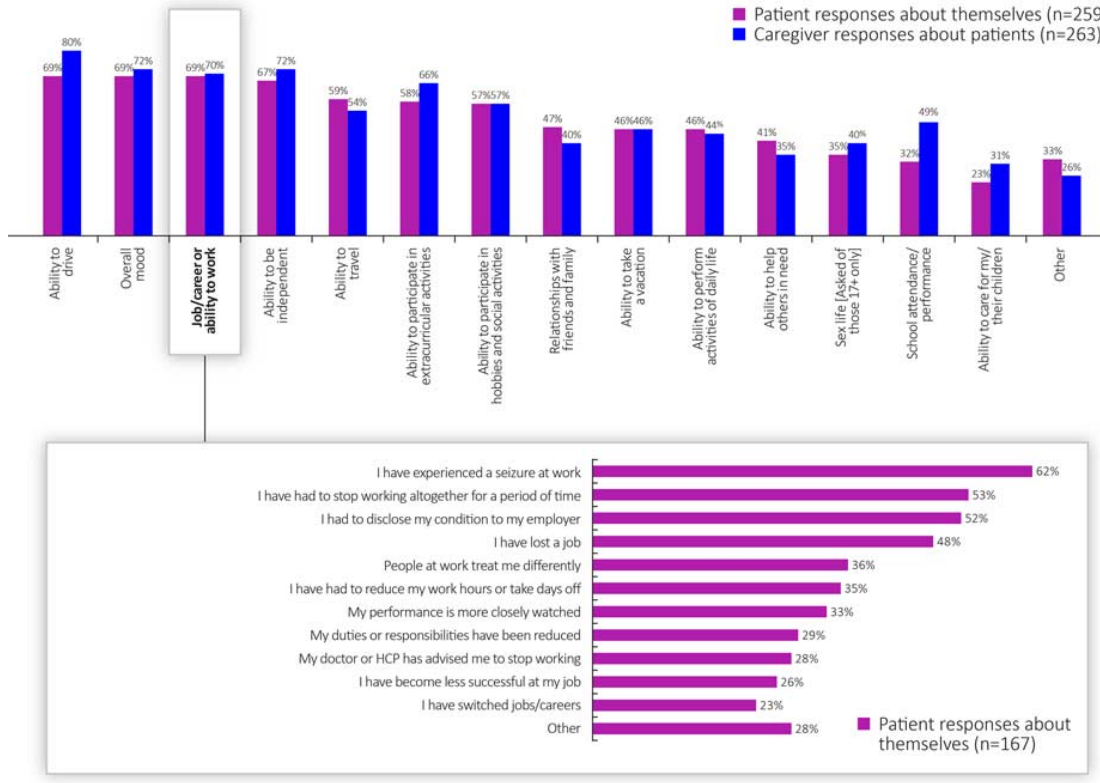


FIGURE 1. Negative impacts of seizure clusters on patients' lives and work/employment (inset). The n values shown reflect the unweighted base; percentages shown are based on the weighted base, which may vary slightly for individual items due to the contingent nature of the survey. Percentages represent "very" or "somewhat" negative impact. HCP indicates health care provider.

"stressed," or "depressed"), whereas <5% of patients or caregivers chose adjectives such as "hopeful," "safe," or "calm." Consider also that 75% of all patients somewhat or strongly agreed they live in fear of having a seizure at any time. As a whole, these survey results portray a patient population that is bearing a psychological toll due to SC.

Despite the clear need to improve conditions, there are no national or international treatment guidelines for SC, and treatment is highly individualized according to institution and physician. Benzodiazepines are generally considered mainstay for seizure rescue treatment; however, currently available outpatient rescue treatments seem to have miminal impact on clinical care, as these survey results indicate most people are not using rescue medications and preferentially seek out ER care as their first option for managing a SC. Some possible reasons suggested by the survey are lack of seizure emergency plans, poor physician-patient communication, emotional barriers (eg, exhaustion, fear), route of administration concerns (eg, rectal), and acceptance by patients and/or caregivers of a low QOL. Regardless of the reasons, the personal and societal impact of patient lack of use of rescue treatments can be substantial. For example, 1 study demonstrated that the use of

TABLE 3. Patient Emotional and Financial Burden of SC

	Somewhat Agree	Strongly Agree	Total Agree
SC cause significant emotional burden			
Patients (n = 259)	37	43‡	80
Caregivers (n = 263)	40	31	71
Clinicians (n = 339)	63*†	29	92*†
SC cause significant financial burden			
Patients (n = 259)	33	42†‡	74†
Caregivers (n = 263)	32	22‡	55
Clinicians (n = 339)	68*†	15	83*†

The n values shown reflect the unweighted base, which may vary slightly for individual items due to the contingent nature of the survey.
SC indicates seizure clusters.
*$P < 0.05$ versus patients.
†$P < 0.05$ versus caregivers.
‡$P < 0.05$ versus clinicians.

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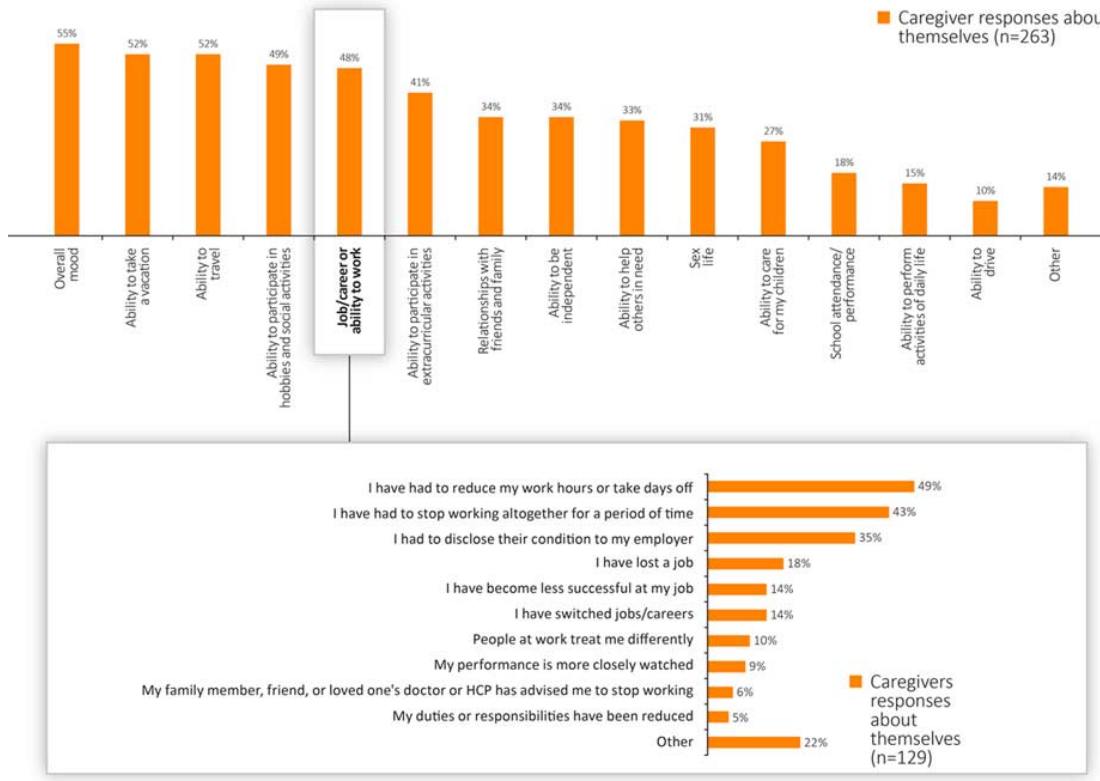


FIGURE 2. Negative impacts of seizure clusters on caregivers' lives and work/employment (inset). The n values shown reflect the unweighted base; percentages shown are based on the weighted base, which may vary slightly for individual items due to the contingent nature of the survey. Percentages represent "very" or "somewhat" negative impact. HCP indicates health care provider.

effective home rescue medication for the treatment of repetitive seizures in pediatric patients can reduce the high level of parental stress associated with ER visits.[18] In addition, better SC management would be expected to lead to economic benefits. These survey data suggest possible overutilization of ER services, potentially leading to excessive costs of care.[15] In addition, lost work time for patients/caregivers is a major contributor to indirect costs.[22] If patients and caregivers more clearly understand the seizure emergency plan and are able to react appropriately to control the episode and/or to avoid unnecessarily utilizing ER resources as a first line of defense, the ability to reduce costs could be considerable. Taken together, these data suggest that improved treatment options and standardized approaches to SC management may give patients and caregivers a deserved expectation of patient-centered care, the ability to self-advocate, and lead to economic benefits.

The survey described here is unique in that it included queries specifically about SC and collected data independently from patients, caregivers, and clinicians. This provides an opportunity to characterize the SC experience from multiple perspectives and assess whether these groups were in agreement. Across many questions, responses between clinicians and patients/caregivers showed a significant disconnect in perceived SC impact, often reflecting a more optimistic view by clinicians. For example, significantly more clinicians felt a fulfilling life was possible relative to patients or caregivers, and significantly more patients than clinicians strongly agreed that SC limit their social life. Regardless of the nature or direction of the discrepancy, most queries showed a statistical difference between clinicians and either caregivers or patients, underscoring the need for improved communication. With new treatment options becoming available, improved communication may lead to improved patient care.

Although most patients and caregivers were generally satisfied with the care and explanations provided by clinicians, SC management also was characterized differently by patients and clinicians, suggesting clinical recommendations are not understood or implemented. Of topics reported as being discussed during most clinic visits (Fig. 3), all showed a significant discrepancy between the percentages of clinicians versus patients or caregivers recalling the topic had been covered. Among the most worrisome findings is that only 30% of patients reported having a seizure emergency plan. This is far lower than the percentage of doctors who reported communicating an emergency plan to their patients, again highlighting disconnect between clinicians and patients, and revealing a potentially dangerous consequence due to lack of adequate communication. One way physicians may begin to address this issue is to ensure that treatment plans are understandable to the patient/caregiver and feasible for that particular patient. More frequent reviews of the plan and emphasizing the importance would also model for the patient that integration of seizure emergency plans need to be a part of the overall management of SC. Clinicians also should consider teach-back techniques or provide home aids, such as a written plan, that serve as reminders under the stressful circumstances of

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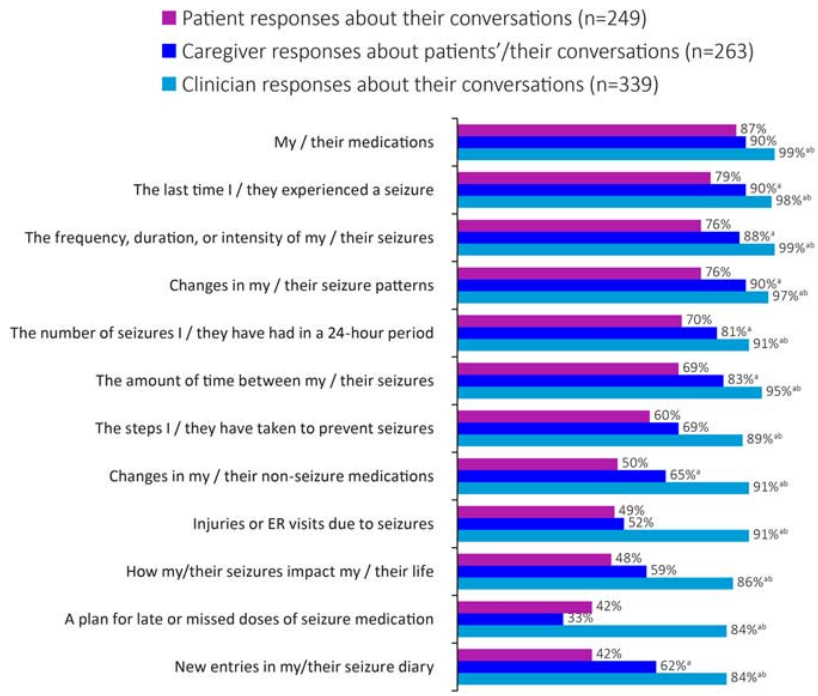


FIGURE 3. Topics discussed with health care provider on more than half of visits/every visit. The n values shown reflect the unweighted base; percentages shown are based on the weighted base, which may vary slightly for individual items due to the contingent nature of the survey. ER indicates emergency room. [a]$P<0.05$ versus patient responses. [b]$P<0.05$ versus caregiver responses.

SC. More attention has been given to these efforts recently, including development and refinement of a clinical decision aid (MINDSET) that facilitates a shared decision-making process during clinic visits.[23] In addition, understanding gaps in patient care and management of SC is not only important for specialists who play a significant role in long-term care (ie, epileptologists and neurologists), but also for primary care physicians and pediatricians, ER personnel, neurosurgeons, and psychiatrists who are likely to encounter SC in their practice. Cooperative efforts by all health care providers would help provide comprehensive quality care for SC patients.

Many published studies using validated QOL scales and/or other validated measures of burden (eg, depression, anxiety, or sleep scales) have proposed a multitude of predictive factors for "burden" in epilepsy patients, including depression and seizure severity/frequency.[24–27] Though not as well studied, predictors of caregiver burden in epilepsy have also been reported and vary widely.[16,17] Recently, Karakis et al[17] reported that increased caregiver burden was associated with higher number of antiepileptic drugs, poorer patient neuropsychological state, decreased patient QOL, and lower caregiver education level. Our evaluation of these survey data did not include regression analyses to determine correlation between burden and potential predictive factors for either seizure disorders in general or SC specifically. Nevertheless, our survey data are consistent with these findings that suggest clinicians should incorporate caregivers into assessments/treatment plans to optimize patient care.

Limitations in the design of this survey include the self-reported nature of the study, varied sample sources, online bias, and unlinked participant groups. As the survey is self-reported, there is the unavoidable risk of recall bias, and responses regarding seizure frequency were not confirmed with physicians. In regards to sample sources, participants recruited via the Harris Poll Online panel may differ from those recruited from The Epilepsy Foundation; for example, participants from The Epilepsy Foundation may be more active and engaged in the epilepsy community, or may represent a more severe population. Bias is also expected with online surveys; though the online method enables inclusion of individuals more easily than the telephone, it may limit reaching more severe patients (eg, those whose condition limits online use). In our survey, caregivers were included to help bridge this gap, as there are caregivers who represent more severe individuals than those included in our patient sample. Finally, some of the disconnect observed in these results could be due in part to the fact that patients, caregivers, and clinicians were not necessarily linked and disease severity of patient respondents may have varied compared with the patients of the clinicians and caregivers surveyed. Despite these survey design limitations, the information gathered on this understudied and underserved population of individuals with SC identifies opportunities to optimize patient care and improve communication.

Together, these survey results suggest the need for increased education on managing SC and improved use/availability of rescue therapies to potentially reduce burden of illness. Clinicians should develop seizure emergency plans and discuss rescue therapies with their patients, whereas patients and caregivers need to ask for and utilize these management strategies.

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