

# Epilepsy during the COVID-19 pandemic lockdown: a US population survey

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## ABSTRACT

**Objective.** This study sought to understand issues facing people with epilepsy (PWE) during the lockdown period of the COVID-19 pandemic in the United States.

**Methods.** We conducted a cross-sectional study using a 20-question survey that used SeizureTracker.com, sent to eligible PWE and their caregivers on May 6th, 2020. Questions about demographics and medical history were used to calculate COVID mortality risk odds ratios (OR) compared to a low baseline risk group.

**Results.** In total, 505 responses were collected. Of these, 71% reported no change in seizure rates and 25% reported an increase in seizures, which they attributed primarily to disrupted sleep (63%) and decreased exercise (42%). Mortality risks from COVID-19 had median OR of 1.67, ranging 1.00-906.98. Fear about hospitalization (53%) and concern for loved ones (52%) were prominent concerns. Of the respondents, 5% reported stopping or reducing anti-seizure medications due to problems communicating with doctors, access or cost. Lower-risk COVID patients reported more fear of hospitalization (55% versus 38%,  $p < 0.001$ ) and anxiety about medication access (43% versus 28%,  $p = 0.03$ ) compared with higher-risk COVID patients. Increased anxiety was reported in 47%, and increased depression in 28%. Ten percent without generalized convulsions and 8% with did not know anything about epilepsy devices (VNS, RNS, DBS).

**Significance.** The COVID-19 pandemic presents unique challenges to PWE, including increased seizure rates, problems with access and cost of life-saving medications. Those with lower COVID-19 risk may have been marginalized more than those with higher risk. Efforts to protect PWE during major public health emergencies should take these findings into account.

**Key words:** SARS-CoV-2; pandemic; epilepsy/seizures; antiseizure medication; epidemiology

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Epilepsy is a common neurological disorder, with an estimated prevalence of 1.2% of the United States population, amounting to 3.4 million persons in the U.S [1]. It is also a debilitating condition, with the disease burden of epilepsy ranked second among neurologic conditions in terms of disability-adjusted life years by the WHO's 2010 Global Burden of Disease study [2]. COVID-19, the infectious disease caused by severe

acute respiratory syndrome coronavirus 2 (SARS-CoV-2), was declared a global pandemic on March 11, 2020 [3]. In the face of the global COVID-19 pandemic, an important question to consider is this: how does the pandemic impact people with epilepsy (PWE)?

There are a number of reasons why the epilepsy population warrants special attention during the pandemic. The CDC identified epilepsy as a potential risk

factor for severe illness from COVID-19 [4], despite lack of clear evidence. Furthermore, the incidence of epilepsy is higher in the oldest age groups [5], a known high-risk group for severe illness from COVID-19.

In addition, maintaining seizure control in PWE remains a critical treatment goal during the COVID-19 pandemic. High seizure frequency, particularly generalized tonic-clonic seizures (GTCs), increases the risk of sudden unexplained death in epilepsy (SUDEP) [6, 7]. Furthermore, breakthrough seizures can lead to emergency department (ED) visits, and potentially increase patient exposure to COVID-19. It is not surprising, therefore, that consensus recommendations among epilepsy experts highlighted the importance of maintaining an adequate supply of antiseizure medication (ASM) during the pandemic [8].

The objective of our study was to better understand the factors that affect the experience of PWE during the early COVID-19 pandemic in the United States, particularly during the lockdown period when social distancing was maximally enforced. In particular, given that this was a particularly stressful time for many individuals, we were interested in the unique sources of anxiety or fear that our population was experiencing. Our hypothesis was that a significant portion of our population would have changes in their seizure patterns, disruptions to daily routine, and face challenges with access to healthcare.

## Materials and methods

We conducted a cross-sectional study, specifically a web-based survey, through SeizureTracker™, a web, mobile, wearable and voice-activated self-management application for PWE [9]. Eligible participants included adults (18 years or older) who self-identified as having epilepsy, or caregivers/family members directly answering on behalf of the patient. We therefore did not include respondents who were themselves under 18, or caregivers/family members who personally answered for themselves (not with respect to the patient). Other care providers who were SeizureTracker users (doctors, nurses) were excluded. Eligible users of SeizureTracker were recruited via an email; in addition, the study was posted on the SeizureTracker website. Respondents therefore needed to be familiar with navigating the survey in a web-based environment. Informed consent was given electronically. The survey was sent out on May 6, 2020 and closed on May 19, 2020. Of note, at the time the survey was initially sent out, most states in the US were still in lockdown, with several states beginning to re-open during the response collection window. The survey (tables 1 and 2) consisted of 20 multiple choice questions and used question logic to direct

the respondent to relevant questions based on past responses. We sought to gather enough respondents to gain a population-level understanding of PWE during this time. Respondents were able to exit the survey at any time, but any previously completed question responses were included. The first part of the survey addressed demographics and baseline characteristics of the participants, including gender, seizure semiology and frequency, and comorbid medical conditions. The second part sought to determine how variables of interest of PWE have been impacted since the pandemic.

Survey results were collected following closure of the survey on May 19, 2020. Respondents were able to exit the survey at any time. All survey responses, including both completed and partially completed surveys, were included. We therefore reported data based on the number of responses to each specific question, rather than the total number of respondents who answered from the beginning of the survey.

Outcomes of interest were limited to the survey responses. Some responses included “None” and “Other” options, but free-text responses were excluded from analysis in order to prevent accidental disclosure of any personally identifying information to investigators. Responses were self-reported and not verified, as we could not trace responses back to individuals. No follow-up data was collected.

As part of the data analysis, we developed a calculator to estimate mortality risk from COVID-19 using data published from a large case series of 44,672 patients from China [10]. This paper compared characteristics of survivors and non-survivors from COVID-19, including age, gender and comorbidities, and odds ratios (OR) for different demographic features associated with death (e.g. gender, presence or absence of diabetes, hypertension, etc.). We selected a baseline population (females, aged 20-40, with no comorbidities) based on lowest reported death rate [10]. Treating each factor independently (i.e. no interaction terms), we multiplied the OR values for each factor (age, gender, hypertension, diabetes, cardiovascular disease, respiratory disease, and cancer) for patients in order to obtain an estimated overall risk of COVID-19 death compared to the baseline population. This calculation has not been independently validated, however, no formal validated mortality calculator was available at the time of this analysis, and the study we used was one of the largest case series available with risk factor contributions calculated [10]. The COVID-19 OR values can therefore be considered preliminary estimates, pending a more comprehensive understanding of COVID-19.

We performed subgroup analyses to assess responses to certain questions from particular groups, including respondents with high COVID mortality ( $OR \geq 12$ ) versus low COVID mortality ( $OR < 12$ ) scores, patient

▼ **Table 1.** Demographic information of the survey population. The denominator of responses for each particular question is listed, as respondents could exit survey at any time.

Variable (respondents to each question/total number respondents)	Descriptor	Total number (%)
Type of survey respondent (n=505/505)	Patient	255 (50%)
	Caregiver	230 (46%)
	Physician	3 (1%)
	Nurse Practitioner	1 (0%)
	Nurse	5 (1%)
	Other	17 (3%)
	Patient gender (n=463/505)	Male
Female		267 (58%)
Other		2 (0%)
Age of patient (n=480/505)	0-3 years	8 (2%)
	4-10 years	49 (10%)
	11-17 years	67 (14%)
	18-30 years	105 (22%)
	31-40 years	85 (18%)
	41-50 years	73 (15%)
	51-60 years	48 (10%)
	61-70 years	43 (9%)
	71-80 years	8 (2%)
81+ years	4 (1%)	
Practitioner managing epilepsy (n=462/505)	Primary care physician	17 (4%)
	General neurologist	180 (39%)
	Epileptologist	246 (53%)
	Other	19 (4%)
Seizure semiology (n=465/505)	Simple Partial/Focal aware	161 (35%)
	Complex partial/Focal unaware	230 (49%)
	Secondarily generalized	78 (17%)
	Absence or atypical absence	163 (35%)
	Generalized tonic-clonic	230 (49%)
	Atonic	61 (13%)
	Myoclonic	107 (23%)
	Status epilepticus	73 (16%)
	Clusters of seizures	123 (26%)
	Nocturnal	196 (42%)
	Other	15 (3%)
Seizure frequency (n=466/505)	More than once per day	57 (12%)
	Between daily and weekly	109 (23%)
	Between weekly and monthly	137 (29%)
	Less than 1 per month	101 (22%)
	Less than 1 per year	62 (13%)

▼ **Table 1.** Demographic information of the survey population. The denominator of responses for each particular question is listed, as respondents could exit survey at any time (*continued*).

Variable (respondents to each question/total number respondents)	Descriptor	Total number (%)
<b>Other medical conditions (n=164/505)*</b>	Lung disease	49 (30%)
	Heart disease	25 (15%)
	Immunosuppression	67 (41%)
	Obesity	59 (36%)
	Diabetes	17 (10%)
	Kidney disease	10 (6%)
	Liver disease	5 (3%)
	Cancer	9 (5%)
<b>Have you ever had a Vagus Nerve Stimulator (VNS), Responsive Neuro Stimulator (RNS), or Thalamic Deep Brain Stimulation (DBS) implant? (n=453/505)</b>	Yes	106 (23%)
	No	305 (67%)
	I don't know anything about these devices	41 (9%)
<b>Please check which device you have had implanted (n=106/505)</b>	VNS	94 (89%)
	RNS	15 (14%)
	DBS	1 (1%)

\*114 respondents selected "Other" which we did not include for analysis

▼ **Table 2.** Responses to the main survey about impact of various domains during the COVID-19 global pandemic.

Variable	Descriptor	Total number (%)
<b>Change in seizure frequency (n=463/505)</b>	Increase in seizures	116 (25%)
	No significant change	329 (71%)
	Decrease in seizures	18 (4%)
<b>Reasons for increased seizures (n=109/505)</b>	Fear of COVID-19	45 (41%)
	Disrupted sleep routine	69 (63%)
	Changes in medication routine	25 (23%)
	Changes in job/income status	24 (22%)
	Worsening of depression/anxiety	51 (47%)
	Increased use of alcohol	6 (6%)
	Increased use of illicit drugs	2 (2%)
	Decrease in regular exercise	46 (42%)
	Other	36 (33%)
<b>Reasons for decreased seizures (n=18/505)</b>	Improved sleep routine	10 (56%)
	Changes to medication routine	8 (44%)
	Less stress	10 (56%)
	Decrease in illicit drug use	0 (0%)
	Decrease in alcohol use	0 (0%)
	Increase in exercise	6 (33%)
	Other	8 (44%)
<b>Change in anti-seizure medications (n=460/505)</b>	Stopped taking anti-seizure medication(s)	3 (1%)
	Taking less anti-seizure medication(s)	18 (4%)
	No change in anti-seizure medication(s)	367 (80%)
	Taking more anti-seizure medication(s)	64 (14%)
	Do NOT take anti-seizure medication(s)	8 (2%)

▼ **Table 2.** Responses to the main survey about impact of various domains during the COVID-19 global pandemic (*continued*).

<b>Reasons for change in seizure medications (n=85/505)</b>	Problems paying for medication(s)	2 (2%)
	Problems accessing medication(s)	4 (5%)
	Problems communicating with doctor	7 (8%)
	Problems remembering to take medication(s)	4 (5%)
	Concern is it not safe to take medication(s)	1 (1%)
	Doctor recommended I make this change	60 (71%)
	Another reason not listed	29 (34%)
<b>Change in medications for other conditions (n=457/505)</b>	Stopped taking these medication(s)	5 (1%)
	Taking less of these medication(s)	10 (2%)
	No change in these medication(s)	310 (68%)
	Taking more of these medication(s)	38 (8%)
	Do NOT take these medication(s)	93 (20%)
<b>Reasons for change in medications for other conditions (n=50/505)</b>	Problems paying for medication(s)	3 (6%)
	Problems accessing medication(s)	5 (10%)
	Problems communicating with doctor	4 (8%)
	Problems remembering to take medication(s)	5 (10%)
	Concern is it not safe to take medication(s)	3 (6%)
	Doctor recommended I make this change	31 (62%)
	Another reason not listed	17 (34%)
<b>What worries you as a patient (or care provider of a PWE)? (n=411/505)</b>	Fear/anxiety about COVID-19	206 (50%)
	Fear/anxiety about going to the ED/hospital	240 (58%)
	Fear/anxiety about access to medication(s)	185 (45%)
	Fear/anxiety about mental health	154 (37%)
	Fear/anxiety about job/income status	122 (30%)
	Fear/anxiety about family members/loved ones	236 (57%)
	Other	46 (11%)
<b>What worries you the most as a patient (or care provider of a PWE)? (n=378/505)</b>	Fear/anxiety about COVID-19	56 (15%)
	Fear/anxiety about going to the ED/hospital	114 (30%)
	Fear/anxiety about access to medication(s)	53 (14%)
	Fear/anxiety about mental health	35 (9%)
	Fear/anxiety about job/income status	25 (7%)
	Fear/anxiety about family members/loved ones	95 (25%)
<b>Are you concerned about the functioning of your (or the person you care for) device(s)? (n=100/505)</b>	Concern about cancelled/limited office visits	42 (42%)
	Difficulty communicating with doctor's office	12 (12%)
	Concerns about going to the ED/hospital	16 (16%)
	No concerns	51 (51%)
<b>Has there been any change to your (or the person you care for) sleep routine? (n=449/505)</b>	Sleep has worsened	192 (43%)
	Sleep has been unchanged	207 (46%)
	Sleep has improved	49 (11%)
<b>Has there been any change to your (or the person you care for) mood? (n=420/505)</b>	More depressed	125 (30%)
	Less depressed	7 (2%)
	More anxious	209 (50%)
	Less anxious	11 (3%)
	Mood is unchanged	150 (36%)
<b>Have you experienced any decreases in your pay or your family's pay from your job(s)? (n=447/505)</b>	Yes	135 (30%)
	No	219 (49%)
	Does not apply to me	93 (21%)

versus caregiver respondents, respondents with pre-existing job/income versus those without pre-existing income, and patients with generalized convulsions (whether “GTC” or “secondarily generalized”) versus those without generalized convulsions. We chose these groups for subgroup analysis because we were interested in the unique challenges confronting patients with higher risk of mortality from COVID-19 or SUDEP. Statistical tests were computed using the Chi-Squared test with Yates correction.

### Standard protocol approval, registration, and patient consent

No patient identifying information or protected health information was collected throughout this process. The study protocol and materials were reviewed by the BIDMC Institutional Review Board (IRB) and deemed exempt. Written informed consent was obtained from all patients (or guardians of patients) participating in the study online.

## Results

A total of 22,221 survey invitations were emailed to SeizureTracker users. Among these emails, 5,999 were opened, 660 clicked through to the website, and 505 participants ultimately responded. A summary of the responses from the survey is provided in *table 1* for demographic data and *table 2* from the main survey. Response numbers varied for each question, because respondents were able to exit the survey at any point during the survey. Therefore, response numbers were listed for each individual question, out of a total denominator of 505 respondents who began the survey.

Increasing numbers of patients exited the survey before completion, accounting for reduced responses in subsequent questions (*table 1*). Half of the respondents self-identified as having epilepsy ( $n=255$ , 50%), and a similar number were caregivers of PWE ( $n=230$ , 46%). The majority of patients were female ( $n=267$ , 58%) and 18-30 years in age ( $n=105$ , 22%). There was a range of reported seizure types. The majority of respondents reported having generalized convulsions, i.e. GTCs or secondarily generalized seizures ( $n=267$ , 57%). Almost a quarter reported either vagus nerve stimulator (VNS), responsive neurostimulation (RNS), or thalamic deep brain stimulation (DBS) devices ( $n=106$ , 23%). A spectrum of comorbid medical conditions was seen. Of note, 114 respondents indicated that they had “other” medical conditions, which we chose to remove from data reporting (*table 1*) as the study was mostly focused on established medical

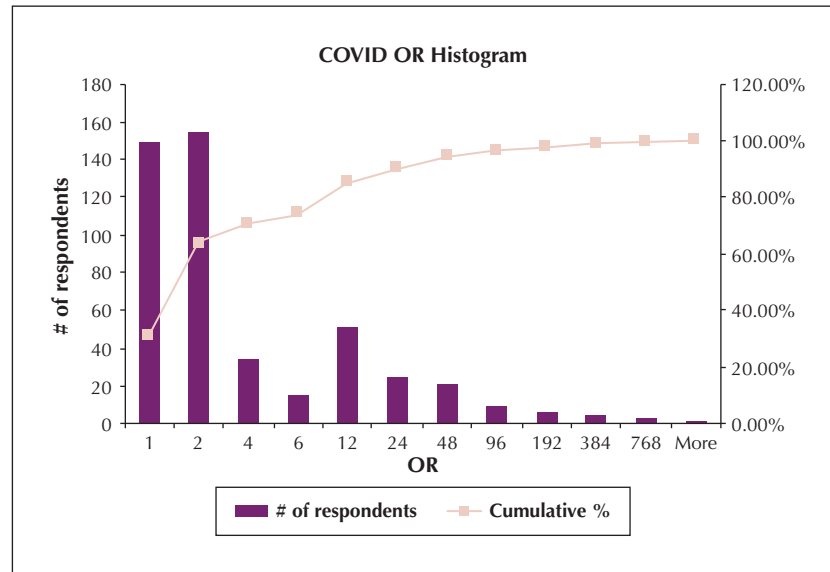
conditions that increase COVID risk (such as underlying lung disease).

The majority of participants reported no change in seizure frequency ( $n=329$ , 71%) and a quarter of patients reported increased seizure frequency ( $n=116$ , 25%) during the pandemic. Among the reasons for increased seizure frequency, disrupted sleep routine ( $n=69$ , 63%) and decreased exercise ( $n=46$ , 42%) were most frequently cited. When asked about sources of anxiety during the pandemic, fear or anxiety about going to the ED or hospital ( $n=240$ , 53%) and concern for family members/loved ones ( $n=236$ , 52%) were the two most prevalent reasons. When respondents had to choose the single greatest source of fear or anxiety, going to the ED or hospital was most frequently chosen ( $n=114$ , 29%). Five percent of patients either reported taking less ( $n=18$ , 4%) ASMs or stopped taking ASMs altogether ( $n=3$ , 1%). Clarifying these changes, some reported problems communicating with their doctor ( $n=7$ , 8%), accessing medications ( $n=4$ , 5%), and cost ( $n=2$ , 2%). A similar proportion of responses was seen with reasons for change in medications for other conditions, particularly regarding access to medications unrelated to epilepsy ( $n=50$ , 10%) and issues regarding communication ( $n=4$ , 8%). Almost half of the respondents reported worsened sleep ( $n=192$ , 43%) and increased anxiety ( $n=209$ , 50%) during the pandemic. A total of 479 respondents were included for calculation of their estimated COVID mortality odds ratio (OR). The distribution of COVID mortality is provided in *figure 1*. The median OR was 1.67 with a skewed distribution (range 1.00 - 906.98). Given the baseline population had a mortality risk of 0.2%, this meant the median mortality risk was 0.3%.

Regarding subgroup analyses, we found that patients with a pre-existing source of income were more anxious about job/income status compared to those who did not have pre-existing income ( $p<0.01$ ). There were no significant differences in responses among patients with generalized convulsions versus those without generalized convulsions. These results were therefore not reported further. Detailed subgroup analyses regarding responses to “What worries you as a patient (or care provider of a person) with epilepsy during the COVID-19 pandemic?” are provided in *tables 3-5*, as determining the unique sources of anxiety or fear among our population was one of our primary objectives.

## Discussion

Our objective was to better understand the factors that affect the experience of PWE during the COVID-19 pandemic lockdown period in the United States



■ **Figure 1.** Histogram of distribution of COVID mortality risk in our population, where OR of 1 corresponds to the low risk encountered by females aged 20-40 (baseline group), who had a reported mortality risk of 0.2%. Many of the respondents had OR values that were relatively low, while a sizable fraction had very large mortality risk scores.

▼ **Table 3.** Sources of fear/anxiety in response to the question “What worries you as a patient (or care provider of a person) with epilepsy during the COVID-19 pandemic? Select all that apply” according to low COVID OR versus high COVID OR. Response numbers only included respondents who answered all questions required to determine the calculation.

	COVID-19	Going to the ED/hospital	Access to medication	Mental health	Job/income status	Family members/loved ones	Other
<b>Low COVID OR (&lt;12)</b> (n=355/411)	178 (50%)	214 (60%)	166 (47%)	133 (37%)	111 (31%)	205 (58%)	37 (10%)
<b>High COVID OR (&gt;12)</b> (n=56/411)	28 (50%)	26 (46%)	19 (34%)	21 (38%)	11 (20%)	31 (55%)	9 (16%)

▼ **Table 4.** Sources of fear/anxiety in response to the question “What worries you as a patient (or care provider of a person) with epilepsy during the COVID-19 pandemic? Select all that apply” according to patient versus caregiver respondents. Response numbers only included respondents who answered all questions required to determine the calculation.

	COVID-19	Going to the ED/hospital	Access to medication	Mental health	Job/income status	Family members/loved ones	Other
<b>Patients</b> (n=202/411)	97 (48%)	<b>90</b> (45%) <sup>1</sup>	82 (41%)	<b>94</b> (47%) <sup>1</sup>	<b>78</b> (39%) <sup>1</sup>	<b>131</b> (65%) <sup>1</sup>	18 (9%)
<b>Caregiver respondents</b> (n=209/411)	109 (52%)	<b>150</b> (72%) <sup>1</sup>	103 (49%)	<b>60</b> (29%) <sup>1</sup>	<b>44</b> (21%) <sup>1</sup>	<b>105</b> (50%) <sup>1</sup>	28 (13%)

<sup>1</sup> Denotes statistical significance (p-value <0.05) with Chi-square test performed with Yates correlation.

▼ **Table 5.** Sources of fear/anxiety in response to the question “What worries you as a patient (or care provider of a person) with epilepsy during the COVID-19 pandemic? Select all that apply” according to patients with low COVID OR versus caregivers with low COVID OR. Response numbers only included respondents who answered all questions required to determine the calculation.

	COVID-19	Going to the ED/hospital	Access to medication	Mental health	Job/income status	Family members/loved ones	Other
<b>Patients with Low COVID OR (n=152/355)</b>	72 (47%)	<b>68 (45%)<sup>1</sup></b>	66 (43%)	<b>74 (49%)<sup>1</sup></b>	<b>68 (45%)<sup>1</sup></b>	<b>102 (67%)<sup>1</sup></b>	11 (7%)
<b>Caregiver Respondents with Low COVID OR (n=203/355)</b>	106 (52%)	<b>146 (72%)<sup>1</sup></b>	100 (49%)	<b>59 (29%)<sup>1</sup></b>	<b>43 (21%)<sup>1</sup></b>	<b>103 (51%)<sup>1</sup></b>	26 (13%)

<sup>1</sup> Denotes statistical significance (p-value <0.05) with Chi-square test performed with Yates correlation.

when social distancing was maximally enforced. This survey of PWE and their caregivers indeed highlighted a number of important challenges faced during this time, including impacts on seizure burden, lifestyle, access to care, and mental health.

The National Syndromic Surveillance Program (NSS) determined that there was a significant decline in ED visits during the early COVID-19 pandemic, with a 42% reduction between March 29-April 25, 2020 relative to the same time one year earlier [11]. With lower numbers of patients coming to the hospital nationwide, the question emerges: how well were seizures controlled in PWE during this time? We hypothesized that a significant portion of our population had changes in their seizure pattern during the pandemic. We found that while the majority of respondents reported no change in seizure frequency, a striking 25% of our population reported increased seizure frequency. These findings may suggest that this population faces unique health risks which may require unique public health responses during pandemics or other population-wide crises. However, this finding must be interpreted with caution, as it can be difficult to distinguish between a true change and a patient's natural probabilistic variability in seizure frequency [12-15]. This number may also reflect a more direct effect of the COVID-19 lockdown.

There are many potential reasons for increased seizure frequency during the COVID-19 pandemic. The pandemic has dramatically altered many aspects of daily life for the global population, including physical activity, employment, and mental health. Our study found that both disrupted sleep and decrease in exercise accounted for a higher proportion of responses than fear from COVID-19 itself. We believe these

findings further underscore the importance of education and counseling about the daily lifestyles of PWE, an area that may be overlooked during a pandemic. The importance of maintaining regular sleep, healthy dietary and exercise habits, and avoiding drugs and alcohol were highlighted in a consensus statement of epilepsy experts [8]. Our results reinforce this point and suggest that spending the extra time to address lifestyle issues in patient encounters may have an impact on reducing seizure frequency.

By contrast, we found that only 4% (18/463) of respondents reported decrease in their seizure frequency during the lockdown. There are multiple potential reasons to account for this finding, including recall bias, probabilistic variation in natural seizure frequency, reluctance of patients with improved seizures to participate, or a general shift toward increased seizures secondary to stressors or other lifestyle changes throughout this unique time.

It is critical that PWE maintain access to ASMs during times of crisis, as medication adherence dramatically decreases mortality and other morbidity [16]. Seizure freedom, especially from GTCs, is strongly associated with a decreased risk of sudden unexplained death in epilepsy (SUDEP) [7]. Furthermore, when medication-resistant PWE are not receiving an ASM, there is increased risk of SUDEP [7]. Concerns have also been raised about access to medications during the pandemic [17]. Unfortunately, when examining the reasons why patients who either stopped ASMs or took a reduced amount of ASMs during the pandemic (difficulties with communication, access to medications, and cost), the survey showed that PWE faced significant barriers for life-saving treatments during the pandemic. The results also suggest that our



population would benefit from improved communication and increased outreach during the pandemic. Quick phone check-ins from staff in doctors' offices and pharmacies could potentially ease patient concerns but may also save lives. Other creative avenues for outreach can be explored thanks to the expansion of telemedicine.

We assigned each patient a putative odds ratio based on the calculation of COVID mortality risk derived from a large scale study of 44,672 patients [10]. We found that the COVID mortality risk of participants was skewed to the left, with about half of the patients at the baseline mortality range (*figure 1*). There was no statistically significant difference in sources of anxiety identified during the pandemic among patients with higher (>12) versus lower (<12) COVID mortality risk scores (*table 3*). The similar rates of anxiety seen among patients with varying COVID mortality risk underscores the importance of not neglecting the significant portion of PWE who are younger with minimal to no additional medical problems, particularly during a time when attention is often appropriately directed toward patients who are at the highest risk of mortality from COVID-19.

In comparing responses from patients and caregivers with epilepsy, we found that caregivers more frequently chose fear or anxiety about going to the ED/hospital relative to patients (72% versus 45%,  $p<0.01$ ). This trend remained true when comparing patients with low COVID OR versus caregivers with low COVID OR (72% versus 45%,  $p<0.01$ ). We hypothesize that this difference may be attributable to increased familiarity with navigating the healthcare system among patients who are able to participate in their own care. It is also possible that caregivers were more concerned about hospital visits due to restricted visitor policies during the pandemic. Taken together, these results suggest that caregivers of PWE may benefit from support during times of transition in and out of inpatient care.

We also found that, in comparison to caregivers, patient respondents more frequently selected concerns about mental health (47% versus 29%,  $p<0.01$ ) and job/income status (39% versus 21%,  $p<0.01$ ). We believe this finding is indicative of more personal issues that affect patients directly. Concern for loved ones was also more prevalently cited among patients in comparison to caregivers (65% versus 50%,  $p<0.01$ ), supporting the far-reaching effects of the pandemic on the whole family unit during the lockdown period. The pandemic has also significantly impacted the mental health of our population, as about half of respondents reported increased anxiety ( $n=209$ , 47%) and a significant amount felt more depressed ( $n=125$ , 28%). It is already clear that PWE have higher rates of mental health disorders compared to the general population [18]; one meta-analysis found the pooled

prevalence of anxiety and depression to be 20.2% and 22.9%, respectively [19]. This study suggests that it is even more critical to swiftly diagnose and treat mood disorders in PWE during the pandemic.

Patients with neuromodulatory devices (VNS, RNS, DBS) also face unique challenges, as device issues cannot be fully addressed in the virtual telemedicine setting. We wanted to highlight this population in order to gain a basic understanding of how aware patients were of advanced treatment options, which in turn may correlate with the level of patient and provider engagement of all potential options for epilepsy treatment. Our study included a disproportionately high number of patients with such devices relative to the general epilepsy population. While speculative, this finding could suggest that our population may be more technologically savvy or engaged with their condition, which may have influenced results. Accordingly, a large proportion of patients with devices reported concern about cancelled/limited doctor's visits as well ( $n=42$ , 40%). Our findings reinforce the challenge of inadequate education about epilepsy devices, as there was a similar rate of respondents who answered "I don't know anything about these devices" among those with generalized convulsions ( $n=22$ , 8%) and those without generalized convulsions ( $n=19$ , 10%). Those with generalized convulsions have a particularly strong need for such education, due to the potential to mitigate a known risk for SUDEP [7, 20].

Our study found a generally low COVID mortality risk (median 0.3%), reflective of the relatively young age of our population (*table 1*). Although speculative, this finding puts into context the fact that our population continues to face challenges during the pandemic in other areas that are not accounted for by typical COVID risk factors, such as seizure frequency, access to medication, mental health, sleep, and impact on job/income.

Our study had several limitations. The study was prone to recall bias (for survey responses) and selection bias (the survey was directed to users of SeizureTracker.com, with a relatively high proportion of patients with epilepsy devices, potentially suggestive of technologically more savvy respondents). All data were self-reported, with no objective information collected. In addition, we conducted a cross-sectional study, rather than a longitudinal study. When we calculated respondents' COVID mortality risk using data from the large Chinese series, it is important to note that this calculator has not been validated. The odds ratio assigned to each patient was putative and based on this single study. We expect that more accurate estimations of mortality risk can be determined based on newer, larger scale epidemiologic studies as more details about COVID-19 become available. However,

at the time of the publication during this COVID pandemic, there are no other validated calculators available that focused on the risk factors we studied. The odds ratio scores computed assumed independence of risk factors, which is unlikely to be a perfectly true assumption. The highest OR calculated was 906, even though the baseline population faced a mortality risk of 0.2%, meaning the highest risk group faced a >100% mortality risk, clearly highlighting model inaccuracy. At the present, the data available from the referenced Chinese study [10] was the largest cohort available with detailed risk factors available, but with insufficient level of detail to address interaction terms for a more accurate calculator. It is expected that future larger studies will further clarify risk of COVID-19 mortality and better stratify risk factors. Overall, results in this study merit further replication to determine follow-up risk and must be interpreted in the context of the early COVID-19 lockdown period.

## Conclusion

In conclusion, our study indicates that PWE and their caregivers face a number of significant challenges during a pandemic. Though a large proportion of our patients had lower risk of mortality from COVID-19, this rather ironically puts our patients at risk of being overlooked by a saturated health care system. Providers should be made aware that even with a lower risk of death from COVID-19, PWE still must contend with many issues, including seizure burden, lifestyle, access to care and medication, and mental health. ■

### Supplementary data.

Summary didactic slides are available at [www.epilepticdisorders.com](http://www.epilepticdisorders.com).

### Acknowledgements and disclosures.

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Mr. Moss is the owner and founder of SeizureTracker.com. Dr. Casassa, Dr. S. Goldenholz and Dr. D. Goldenholz have no conflict of interest to declare.

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## TEST YOURSELF

**(1) Which statement about persons with epilepsy (PWE) and access to medications is false?**

- A. When medication-resistant PWE are not receiving an anti-seizure medication (ASM), there is increased risk of sudden unexplained death in epilepsy (SUDEP).
- B. PWE may have difficulty accessing ASMs during the pandemic.
- C. Medication adherence in PWE is invariably associated with seizure frequency.
- D. Survey data suggests that PWE may benefit from increased outreach during the COVID-19 pandemic.

**(2) Which statement about the mental health of persons with epilepsy (PWE) is false?**

- A. PWE have a higher rate of anxiety compared to the general population.
- B. PWE have a higher rate of depression compared to the general population.
- C. Fear or anxiety about emergency department (ED) visits may play a role in reduced hospitalizations for PWE during the COVID-19 pandemic.
- D. Patients with a higher risk of developing severe illness from COVID-19 have higher rates of depression/anxiety during the pandemic.

**(3) According to the survey, which of the following reasons were most frequently cited for increased seizure frequency during the COVID-19 lockdown?**

- A. Disrupted sleep routine.
- B. Increased exercise.
- C. Changes in job/income status.
- D. Increased use of alcohol.

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*Note: Reading the manuscript provides an answer to all questions. Correct answers may be accessed on the website, [www.epilepticdisorders.com](http://www.epilepticdisorders.com), under the section "The EpiCentre".*

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