

# Seizure control, stress, and access to care during the COVID-19 pandemic in New York City: The patient perspective

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## Abstract

**Objective:** Our epilepsy population recently experienced the acute effects of the COVID-19 pandemic in New York City. Herein, we aimed to determine patient-perceived seizure control during the surge, specific variables associated with worsened seizures, the prevalence of specific barriers to care, and patient-perceived efficacy of epilepsy care delivered via telephone and live video visits during the pandemic.

**Methods:** We performed a cross-sectional questionnaire study of adult epilepsy patients who had a scheduled appointment at a single urban Comprehensive Epilepsy Center (Montefiore Medical Center) between March 1, 2020 and May 31, 2020 during the peak of the COVID-19 pandemic in the Bronx. Subjects able to answer the questionnaire themselves in English or Spanish were eligible to complete a one-time survey via telephone or secure online platform (REDCap).

**Results:** Of 1212 subjects screened, 675 were eligible, and 177 adequately completed the questionnaire. During the COVID-19 pandemic, 75.1% of patients reported no change in seizure control, whereas 17.5% reported that their seizure control had worsened, and 7.3% reported improvement. Subjects who reported worsened seizure control had more frequent seizures at baseline, were more likely to identify stress and headaches/migraines as their typical seizure precipitants, and were significantly more likely to report increased stress related to the pandemic. Subjects with confirmed or suspected COVID-19 did not report worsened seizure control. Nearly 17% of subjects reported poorer epilepsy care, and 9.6% had difficulty obtaining their antiseizure medications; these subjects were significantly more likely to report worse seizure control.

**Significance:** Of the nearly 20% of subjects who reported worsened seizure control during the COVID-19 pandemic, stress and barriers to care appear to have posed the greatest challenge. This unprecedented pandemic exacerbated existing and created new barriers to epilepsy care, which must be addressed.

## KEYWORDS

access to care, COVID-19, epilepsy, pandemic, stress, teleneurology

## 1 | INTRODUCTION

Although the initially recognized and most common presenting symptoms of SARS-CoV-2 infection are respiratory, there is a growing body of literature on its neurologic manifestations.<sup>1</sup> Anosmia and ageusia have been frequently reported. The most common serious neurologic manifestations are encephalopathy and stroke, including large vessel strokes in young otherwise low-risk individuals.<sup>2–4</sup> We reported a high rate of epileptiform abnormalities on the electroencephalograms (EEGs) of acutely ill patients with SARS-CoV-2 infection and altered mental state.<sup>5</sup> There are also reports of new onset seizures and encephalitis.<sup>6,7</sup> However, there is a paucity of data on its impact on chronic neurologic conditions, including epilepsy. One study found that patients with epilepsy were not at significantly higher risk for COVID-19–associated mortality.<sup>8</sup> Two small cross-sectional questionnaire studies explored epilepsy patients' seizure control and neurologic care; one study reported that one-third of patients noted increased seizure frequency, but neither examined variables associated with worsened seizure control.<sup>9,10</sup> A third study reported that poor sleep quality was associated with worse seizure control.<sup>11</sup>

This study was designed to explore and assess whether the pandemic's broad societal impacts, such as barriers to accessing care and increased stress, as well as SARS-CoV-2 infection would worsen seizure control. It represents a cross-sectional questionnaire study in a heavily impacted region (Bronx, New York City) to investigate the impact of suspected SARS-CoV-2 infection and the broader COVID-19 pandemic on epilepsy patients. We determined the prevalence of patient-perceived seizure control (frequency and/or severity) during the pandemic and whether specific variables (including suspected COVID-19 status, stress level, demographics, epilepsy characteristics, and access to care) were associated with this change. We also investigated epilepsy patients' access to neurologic care during the pandemic, including specific barriers to care and patient-perceived efficacy of neurologic care delivered via telephone and live video visits.

## 2 | MATERIALS AND METHODS

Adult (>18 years of age) patients with epilepsy with a scheduled follow-up visit with an epileptologist at an urban Comprehensive Epilepsy Center (Montefiore Medical Center) between March 1, 2020 and May 31, 2020 were eligible. This time range reflects the peak of the COVID-19

## Key Points

- The nearly 20% of subjects who reported worsened seizure control during the COVID-19 peak tended to report more severe epilepsy and seizures precipitated by stress as well as increased stress related to the pandemic
- Barriers to care, including difficulty obtaining antiseizure medications, were more common among subjects who reported worse seizure control
- There is a need for more effective delivery of neurologic care via telehealth tools

pandemic in New York City. Patients able to answer the questionnaire themselves in either English or Spanish were eligible. The questionnaire could not be completed by caregivers, given the nature of the self-report. Eligible subjects had a visit scheduled, regardless of whether their visit was completed, canceled, or rescheduled. Exclusion criteria included new patients, patients without a confirmed diagnosis of epilepsy, and patients with EEG-confirmed psychogenic nonepileptic seizures (PNES). This study and the remote telephone consent process were approved by the Einstein/Montefiore Institutional Review Board.

Of 1212 scheduled patient visits, 537 were excluded because 233 patients were unable to answer the questionnaire unassisted due to their neurologic baseline (nonverbal, aphasia, or severe intellectual disability); six patients were deceased, three of whom died because of COVID-19 respiratory failure (none had documented seizures during their illness); 182 were new patient visits; 98 patients did not have a diagnosis of epilepsy; and 18 patients had EEG-confirmed PNES.

Of 675 eligible patients, 346 could not be reached. The remaining 329 subjects were contacted by a member of the research team (J.D., D.Z., I.M.), who read the oral consent script. Spanish-speaking subjects were contacted by a native Spanish-speaking neurologist (I.M.). Subjects completed the oral informed consent, and then had the option to complete the questionnaire via telephone or via a secure online platform (REDCap). One hundred twenty patients declined to participate, and 26 initially consented but did not complete the questionnaire. Thus, 183 (27% of eligible subjects) completed the survey. Six patients declined to answer the question about seizure control, and their questionnaires were

excluded. The patients' demographic and epilepsy history information, including duration of epilepsy, type of epilepsy, intractable versus nonintractable epilepsy, and number of antiseizure medications, was extracted from medical records.

The questionnaire was created by neurologists in the Montefiore Health System. It consisted of four sections: seizure control at baseline, seizure control during the pandemic, seizure precipitants, and stress and access to care during the pandemic. Seizure control was assessed qualitatively by asking whether seizure control worsened, remained stable, or improved with forced-choice responses, and internally validated. If subjects responded that they had worsened seizure control, they were subsequently asked whether their seizures were more frequent, were more severe, and/or included a new seizure type. The response to this key question about seizure control during the pandemic was also validated quantitatively by soliciting monthly seizure counts.

Subjects were asked whether they had any seizures in 2019. If they answered affirmatively, they were asked whether they had on average one or more seizures per month in 2019. If they responded yes, they were asked to estimate their monthly seizure rate in 2019, with 11 categorical ranges between 0 to 1, 1 to 2, and up to 10 or more. If they responded no, they were asked how many seizures they had in 2019, and an average monthly seizure rate was calculated. Subjects were then asked to provide the number of seizures per month in each of the first 5 months of 2020, and average monthly seizure rates were calculated for January to February and for March to May. The questionnaire was piloted and externally validated with 15 patients and adapted based on their feedback. The questionnaire and consent forms were translated by native Spanish-speaking neurologists, reviewed additionally for clarity, and ultimately translated back into English to confirm accuracy of content.

Data were analyzed using SPSS v26 to determine any statistically significant association between the variables and change in seizure control. Continuous variables were tested for significance using a Mann-Whitney *U* test. The associations between patient-perceived worsening seizure control and categorical variables were tested for significance using a Pearson chi-squared test. Changes in seizure frequency within outcome groups were assessed for statistical significance using a Wilcoxon rank test.

### 3 | RESULTS

#### 3.1 | Background and demographics

Demographic data are presented, and survey responders were compared to eligible patients who did not complete the survey in Table 1. Median patient age was 47 years, 67.8% of subjects identified as female, and 22% completed the survey in Spanish. Regarding racial and ethnic background, 42.4% identified as Hispanic (*n* = 75), 20.3% as Black/African American (*n* = 36), 9.6% as Caucasian/White (*n* = 17), 1.1% as Asian (*n* = 2), 14.1% as Other (*n* = 25), and 12.4% did not answer (*n* = 22). Compared to nonresponders, subjects who completed the survey were more likely to be primarily Spanish-speaking, slightly younger, and more likely to identify as Hispanic or Other. There were no significant gender differences between responders and nonresponders.

Table 2 shows the subjects' epilepsy history data. Median duration of epilepsy was 15 years, 79.7% of patients had focal epilepsy, 10.7% had generalized epilepsy, and for 9.6% epilepsy type was unknown. In 2019, subjects had an average of one seizure per month (calculated median average of 0.08 seizures per month). Subjects were

**TABLE 1** Demographics, epilepsy history, and baseline seizure frequency

Variable	Survey responders, <i>n</i> = 177	Survey nonresponders, <i>n</i> = 498	<i>P</i>
Age, median y	47, IQR = 21, range = 21-79	51.5, IQR = 28, range = 21-93	.017
Gender	31.6% male, <i>n</i> = 56; 67.8% female, <i>n</i> = 120; 0.5% other, <i>n</i> = 1	38.4% male, <i>n</i> = 191; 61.2% female, <i>n</i> = 305; 0.4% other, <i>n</i> = 2	.276
Racial and ethnic background	42.4% Hispanic, <i>n</i> = 75; 20.3% Black/African American, <i>n</i> = 36; 9.6% Caucasian/White, <i>n</i> = 17; 1.1% Asian, <i>n</i> = 2; 14.1% other, <i>n</i> = 25; 12.4% not answered, <i>n</i> = 22	32.3% Hispanic, <i>n</i> = 161; 30.9% Black/African American, <i>n</i> = 154; 17.5% Caucasian/White, <i>n</i> = 87; 1.6% Asian, <i>n</i> = 8; 6.4% other, <i>n</i> = 32; 11.2% not answered, <i>n</i> = 56	<.001
Preferred language	77.9% English, <i>n</i> = 138; 22% Spanish, <i>n</i> = 39	85.9% English, <i>n</i> = 428; 14.1% Spanish, <i>n</i> = 70	.013

**TABLE 2** Epilepsy history and baseline seizure frequency

Duration of epilepsy, median y	15, IQR = 24.75, range = 0-64
Epilepsy type	79.7% focal, n = 141; 10.7% generalized, n = 19; 9.6% unknown, n = 17
Intractable epilepsy	48.5% yes, n = 81; 52.5% no, n = 93
Number of antiseizure medications, median	1, IQR = 1, range = 0-5
Baseline monthly seizure frequency	
2019	Median average = 0.08 seizures/mo, mean = 1.0, IQR = 0.5, range = 0-≥10
Jan & Feb 2020	Median average = 0.0 seizures/mo, mean = 0.61, IQR = 0, range = 0-≥10
Reported change	
Stable seizure control	75.1%, n = 133
Worse seizure control	17.5%, n = 31
Better seizure control	7.3%, n = 13

on 0-5 antiseizure medications (median = 1; four subjects were taking no antiseizure medications), and 48.5% had intractable epilepsy.

### 3.2 | Seizure control during COVID-19 pandemic

In our cohort, 75.1% of subjects (n = 133) reported no change in seizure control during the COVID-19 pandemic, and 17.5% of subjects (n = 31) reported that their seizure control had worsened. When asked to specify how their seizures worsened, 26 subjects reported that they had more seizures, five subjects answered that seizures were more severe, and six reported a new seizure type (six subjects selected more than one option, including four who reported a new seizure type). Thirteen subjects (7.3%) reported improved seizure control with fewer seizures, and two also reported that their seizures were less severe.

### 3.3 | Variables associated with worsened seizure control

There was no significant demographic difference among subjects who reported worsened versus stable or improved seizure control. The majority of subjects in both groups had focal epilepsy (Table 3).

Subjects who reported worsened seizure control during the pandemic had significantly more seizures at baseline. In 2019, this group had a median average of 0.5 seizures per month, whereas those who did not report worsening had a median average of 0.0 seizures per month ( $P < .001$ ). In January and February 2020 (prior to the first reported COVID-19 case in New York City), the subjects who reported worsening seizure control during the pandemic continued to have a statistically significant greater median average monthly seizure rate compared to those who reported no change or improvement (0.5 vs 0.0, respectively,  $P < .001$ ).

This statistically significant difference persisted in the months of March, April, and May 2020 (during the peak of the pandemic); the subjects who reported that their seizures had worsened had a median average of two seizures per month, whereas those who did not worsen maintained their median average of 0.0. Among the 31 subjects who deteriorated during the pandemic, there was a statistically meaningful change in their monthly seizure frequency compared to January and February of 2020 ( $P < .001$ ). There was not a statistically significant change between their monthly seizure frequency in 2019 and January and February 2020 ( $P = .424$ ).

Although the subjects with worsened seizure control were more likely to have intractable epilepsy, this did not reach statistical significance (61.3% vs 44.5%,  $P = .089$ ). These subjects were also more likely to take more antiseizure medications (median = 2 vs 1), but this similarly did not reach statistical significance ( $P = .178$ ). There was a trend toward longer duration of epilepsy among subjects with stable or improved seizure control (16 vs 12 years,  $P = .062$ ).

### 3.4 | Seizure control and COVID-19

Ten percent (n = 18) reported that they had suspected SARS-CoV-2 infection during this 3-month period. The most commonly reported symptoms were cough (9/18), fever (7/18), shortness of breath (7/18), loss of smell (7/18), new headaches (7/18), chest pain (7/18), loss of taste (5/18), diarrhea (5/18), muscle aches (4/18), and sore throat (4/18). Of the 18 subjects who reported suspected COVID-19, seven subjects were tested for the SARS-CoV-2 virus, two subjects reported a positive test, and two required hospitalization.

None of the 18 subjects reported that their seizure control worsened while they were symptomatic with COVID-19. The subjects who experienced worsening seizure control were not more likely to report suspected COVID-19 ( $P = .879$ ). Of the subjects who suspected that they had COVID-19, 22.2% reported worsening seizure control during the pandemic, which was not statistically different from the subjects who never suspected COVID-19 (16.8%,  $P = .829$ ).

**TABLE 3** Variables associated with reported stable or improved versus worsened seizure control during the COVID-19 pandemic

Variable	Patients who reported no change or improved seizure control, n = 146	Patients who reported worsened seizure control, n = 31	P
Age, median y	48, IQR = 25	44, IQR = 11	.231
Gender, female	67.1%, n = 98	66.7%, n = 22	.840
Race/ethnicity	40.4% Hispanic, n = 59; 19.9% Black/African American, n = 29; 11% White/Caucasian, n = 16; 1.4% Asian, n = 2; 13.4% other, n = 20; 13.4% not answered, n = 20	51.6% Hispanic, n = 16; 22.6% Black/African American, n = 7; 3.2% White/Caucasian, n = 1; 0% Asian, n = 0; 16.3% other, n = 5; 6.5% not answered, n = 2	.542
Duration of epilepsy, median y	16, IQR = 26	12, IQR = 9	.062
Epilepsy type			
Focal	78.1%, n = 114	87.1%, n = 27	.524
Generalized	11.6%, n = 17	6.5%, n = 2	
Unknown	10.3%, n = 15	6.5%, n = 2	
Intractable epilepsy	44.5%, n = 65	61.3%, n = 19	.089
Number of antiseizure medications, median	1, IQR = 1	2, IQR = 1	.178
Median average monthly seizure rate			
2019	0, IQR = 0.25, range = 0-≥10	0.5, IQR = 2.42, range = 0-≥10	<.001
Jan & Feb 2020	0, IQR = 0, range = 0-≥10	0.5, IQR = 3.1, range = 0-≥10	<.001
Mar, Apr, May 2020	0, IQR = 0, range = 0-7.5	2, IQR = 6, range = 0-≥10	<.001
Presumed COVID-19, reported no change in seizure control during acute infection	9.6%, n = 14	12.9%, n = 4	.829
Typical seizure triggers			
Stress	26.0%, n = 38	54.8%, n = 17	.002
Poor sleep	10.3%, n = 15	22.6%, n = 7	.059
Headache/migraine	5.5%, n = 8	19.4%, n = 6	.009
Infection	2.1%, n = 3	6.5%, n = 2	.180
Missed medications	19.2%, n = 28	12.9%, n = 4	.410
Menstrual cycle/period	3.4%, n = 5	9.7%, n = 3	.128
Other	19.2%, n = 28	22.6%, n = 7	.666
I have no clear triggers	37.7%, n = 55	22.6%, n = 7	.110
Believe fear of getting COVID-19 worsened seizures	5.5%, n = 8	61.3%, n = 19	<.001
Increased/worsened stress due to the COVID-19 pandemic	50%, n = 73	80.6%, n = 25	.002
Worse sleep due to the COVID-19 pandemic	41.8%, n = 61	48.4%, n = 15	.275
Worse epilepsy care during the COVID-19 pandemic	12.3%, n = 18	38.7%, n = 12	<.001
Difficulty obtaining antiseizure medications	7.5%, n = 11	19.4%, n = 6	.042
Patient canceled a Neurology appointment	20.5%, n = 30	9.7%, n = 3	.369
Neurologist canceled an appointment	26%, n = 38	35.5%, n = 11	.528
Completed a neurology live video visit	21.9%, n = 32	25.8%, n = 8	.735

(Continues)



TABLE 3 (Continued)

Variable	Patients who reported no change or improved seizure control, n = 146	Patients who reported worsened seizure control, n = 31	P
Effective way to get epilepsy care: yes	75%, n = 24/32	50%, n = 4/8	.243
Completed a neurology telephone visit	60.3%, n = 88	58.1%, n = 18	.596
Effective way to get epilepsy care: yes	77.3%, n = 68/88	66.7%, n = 12/18	.626

### 3.5 | Seizure precipitants during the pandemic

Subjects who reported worsening seizure control were significantly more likely to report that stress was a typical seizure trigger (54.8% vs 26.0%,  $P = .002$ ). These subjects were also more likely to identify migraines or other headaches as a seizure precipitant (19.4% vs 5.5%,  $P = .009$ ). Identification of poor sleep as a seizure precipitant also approached statistical significance as being correlated with worsening seizure control (22.6% vs 10.3%,  $P = .059$ ).

When asked about stress related to the pandemic, subjects who reported poorer seizure control were significantly more likely to report increased or worsened stress (80.6% vs 50.0%,  $P = .002$ ). There was no significant difference in the rates of reported worsened sleep across groups during this 3-month period (48.4% vs 41.8%,  $P = .275$ ).

### 3.6 | Access to epilepsy care

Compared to subjects with perceived stable or improved seizure control, those who reported worsened seizure control were significantly more likely to report that their epilepsy care was worse during the pandemic (38.7% vs 12.3%,  $P < .001$ ). These subjects were also more likely to report difficulty obtaining their antiseizure medications during the pandemic (19.4% vs 7.5%,  $P = .042$ ). Subjects most commonly identified difficulty getting to their pharmacies (29.4%, 5/17 patients) and reaching their neurologist (41.2%, 7/17 patients) as the reason for their trouble obtaining antiseizure medications.

Among subjects who reported worsening seizure control, nearly one-half (48.4%, 15/31) did not contact their neurologist or otherwise seek medical care. Only 22.6% (7/31) contacted their neurologist. Approximately one-third (10/31) presented to an emergency room, and 16.1% (5/31) required hospitalization.

When asked about canceled visits, 18.6% of subjects reported canceling a visit, and 27.7% reported that their neurologist had canceled one of their appointments. There was no significant difference among those who reported improved, worsened, or stable seizure control (Table 4).

### 3.7 | Teleneurology and patient satisfaction

During this time period, 22.5% of subjects completed a follow-up neurology visit via video. Of these 40 subjects, 70% felt that the video visit was an effective way to deliver epilepsy care. An additional 16 subjects declined video visits for a variety of reasons, most commonly lack of access to a device with video capabilities (43.8%, 7/16 patients) and

TABLE 4 Access to epilepsy care and teleneurology experience

If your seizures worsened during the COVID-19 pandemic, what did you do?	Called 911: 12.9%, n = 4/31
	Went to the ED: 32.3%, n = 10/31
	Admitted to the hospital: 16.1%, n = 5/31
	Contacted neurologist: 22.6%, n = 7/31
	I did not seek help: 48.4%, n = 15/31
Difficulty obtaining seizure medications	9.6%, n = 17/177
Difficulty getting to pharmacy	29.4%, n = 5/17
Difficulty contacting pharmacy	11.8%, n = 2/17
Difficult reaching physician	41.2%, n = 7/17
Pharmacy did not have medication in stock	17.6%, n = 3/17
Other	11.8%, n = 2/17
Have you canceled a neurology appointment?	Yes: 18.6%, n = 33/177
Has your neurologist canceled an appointment?	Yes: 27.7%, n = 49/177
Have you had a neurology video visit?	Yes: 22.6%, n = 40/177
Did you believe this was an effective way to get your epilepsy care?	Yes: 70.0%, n = 28/40
Have you had a neurology telephone visit?	Yes: 59.9%, n = 106/177
Did you believe this was an effective way to get your epilepsy care?	Yes: 75.5%, n = 80/106

anticipated difficulty with the video visit (31.3%, 5/16). Follow-up neurology visits via telephone were completed by 59.9% of subjects. Of these 106 subjects, 75.5% reported that the telephone visit was an effective way to receive epilepsy care.

Of the 34 subjects who reported dissatisfaction with their initial teleneurology visit, 13 have since had a subsequent one. Seven of those subjects reported that their second teleneurology visit was an effective way to receive epilepsy care; three had live video visits, and four had telephone encounters. Two patients noted that virtual visits are more practical, and one was appreciative that family members who cannot typically join for in-person visits were able to participate. Three subjects reported dissatisfaction with their second teleneurology visit conducted via telephone. When asked to elaborate as to why they preferred a face-to-face interaction, one subject responded that only in-person can the doctor “see your pain.” The remaining three subjects could not be reached.

## 4 | DISCUSSION

During the peak of the COVID-19 pandemic in New York City, 17.5% of our subjects with epilepsy reported worsened seizure control. Among our questionnaire participants, this deterioration appeared to be due to the widespread societal and personal effects of the pandemic, including increased stress and barriers to care, in susceptible patients. Although patients with epilepsy typically report worsening of seizures with intercurrent illness,<sup>12</sup> none of the 18 subjects who suspected SARS-CoV-2 infection at some point during this time period reported worsening of seizure control during their acute illness. If these subjects were correct in presuming their illness was related to SARS-CoV-2 infection, this suggests milder COVID-19 disease manifestations in this small sample. The number of suspected and confirmed COVID-19 cases was small in this cohort, but the subjects who experienced worsening seizure control during the pandemic were not more likely to report suspected COVID-19.

Our diverse subject population reflects the demographics of the Bronx and included Spanish-speakers (22%). Subjects who identify as Hispanic and are primarily Spanish-speakers were more likely to complete the survey than nonresponders (42.4% vs 32.3%, 22% vs 14.1%), which strengthens our study as a representation of an underserved population. Fewer of our subjects identified as Black/African American or Hispanic compared to the 2019 Bronx census data (42.4% vs 56.4% and 20.3% vs 43.6%, respectively), as more than one-quarter of our subjects selected “Other” or chose not to provide their racial/ethnic background.<sup>13</sup> There was no significant difference in the rates of reported worsening seizure control by ethnic or racial background. The previously published studies on seizure control and/or access to epilepsy care did not

comprise such a diverse population, which has been disproportionately impacted by the COVID-19 pandemic.<sup>14–16</sup> Our diverse population is a strength of our study, but it is unclear whether our results will be fully generalizable.

Subjects who reported worse seizure control were significantly more likely to report that stress was a typical seizure trigger and increased stress levels during the pandemic than those reporting stable seizure control. Stress is the most commonly patient-reported seizure precipitant in many studies, suggesting that our patients with epilepsy may be at greater risk for severe psychological distress during this pandemic.<sup>17–20</sup> This important finding suggests that more resources and attention should be devoted to stress management and broader mental health strategies for patients with epilepsy during an ongoing crisis.

Subjects who identified migraines or other headaches as typical seizure triggers were also significantly more likely to report worsening seizure control. One can speculate that common factors, including increased stress, related to the pandemic could also exacerbate chronic migraine, and thus indirectly also impact seizure control, although our participants were not specifically asked about their headache frequency. However, a different survey study of chronic migraine patients found that respondents had fewer migraines and less severe pain during the COVID-19 pandemic.<sup>21</sup>

Subjects who reported a change in their seizure control had on average more frequent seizures than those who did not. This difference persisted before and during the pandemic. In a similar way, subjects who reported worsened seizure control were more likely to have intractable epilepsy, although this did not reach statistical significance, possibly because of the high rates of intractability among patients followed at a comprehensive epilepsy center (48.5%). Patients with more frequent seizures may also be more likely to detect a change in their seizure control over the relatively short time frame in question. Perhaps more patients, including those with infrequent seizures, would report a change if studied over a longer time course.

The greatest concern is the report of worsened access to epilepsy care during the pandemic, which was significantly higher among those reporting poorer seizure control. This perception was not explained by a higher reported rate of canceled visits. However, reported difficulty obtaining antiseizure medications was significantly more likely in the group reporting worsened seizures, which may account in part for the worsened access to care. It is also feasible that these subjects reported worsened access to care because their seizure control had deteriorated.

Access to care limitations during this pandemic is a critical issue. There are several potential future interventions. Although it may be difficult to help patients physically travel to their pharmacies, pharmacies (including mail order pharmacies) should consider expanding delivery to more patients,

particularly those with multiple medical problems, during a pandemic. Another patient-identified barrier to care was difficulty reaching the neurologist because their neurologists were redeployed to COVID-19 units and intensive care units. Developing effective coverage systems to facilitate better communication between patients and their neurologists is a necessary goal.<sup>22–24</sup>

Nearly one-half of the subjects who reported that their seizures worsened did not contact their neurologist or seek other medical care, although patients were not asked why. Frequent telehealth follow-up appointments may be advisable, as brief follow-up appointments may be feasible for both the patients and physicians when completed via telephone or video. However, 30% of subjects who completed a video visit and 25.2% of subjects who completed a telephone visit reported that they did not receive effective care via these modalities. Individual patient expectations for these visits were not acquired. Improved patient satisfaction with subsequent teleneurology encounters may reflect both the physicians' and patients' familiarity and proficiency with teleneurology. Among this small follow-up cohort, their responses may suggest that patients consider video visits to be more effective than telephone encounters. As one patient poignantly remarked, only in-person can the doctor "see your pain." Physicians and other health care providers must work with patients and solicit feedback to make telephone and video visits more effective, especially because teleneurology is expected to become a larger part of care delivery.<sup>25–27</sup>

Interestingly, 7.3% of subjects ( $n = 13$ ) reported that their seizure control had improved, which was an unanticipated finding with several possible explanations. Fewer seizures may simply reflect the natural fluctuations in seizure control. Subjects who reported improved seizure control had a lower median average monthly seizure rate in January and February of 2020 compared to 2019, suggesting that the change preceded the pandemic. The subjects who reported improved seizure control did not report significantly different rates of increased stress or difficulty sleeping, but it is feasible that other lifestyle changes related to the pandemic indirectly improved seizure control. Because of closures of schools, workplaces, and day programs, patients may have benefitted from additional hours of sleep and subsequently improved seizure control. One can also speculate that spending more time at home improved compliance with antiseizure medication regimens and encouraged other healthy lifestyle habits.

## 4.1 | Lessons learned

There are several relevant lessons that our institution will integrate into our practice and that physicians in other parts of the USA and world can preemptively learn from as the COVID-19 pandemic surges elsewhere.

1. The impact of increased stress related to the pandemic appears to be detrimental to seizure control. We should proactively ask our epilepsy patients about their stress levels related to the pandemic and recommend treatment and self-management tools accordingly.
2. We need to ensure that our patients, particularly those with intractable epilepsy, continue to have adequate follow-up and access to antiseizure medications during a pandemic, as nearly one-half of our subjects who reported worsening in seizure control did not seek care. Potential initiatives include more frequent virtual appointments and proactively contacting patients to ensure that they have an adequate supply of their antiseizure medications.
3. Physicians must collaborate with patients, information technology staff, and administrators to make telephone and video visits more effective and improve the patient experience with these modalities, because it is expected that teleneurology will become part of our practices long-term.

## 4.2 | Limitations of the study

A cross-sectional questionnaire survey captures subjects' experiences and perceptions at only one point in time, and thus subjects are answering many questions retrospectively. Bias, particularly recall bias, is unavoidable. Although some patients maintain a seizure diary, many do not, and retrospective seizure counts are not entirely reliable. In addition, we did not extract seizure frequency from the medical records given variable documentation during the pandemic, and in many cases the actual medical encounter did not take place. Six subjects reporting worsening seizure control identified a new seizure type, which is difficult to substantiate, although four of these six subjects reported concurrent changes in seizure frequency or severity. Assessment of seizure precipitants from questionnaire studies is problematic, as recall bias is prevalent and true causality is impossible to establish. It is possible that the increased stress perceived as a precipitant actually reflects a bidirectional relationship, in that worsening seizure control contributed to subjects' increase in stress.

The vast majority of subjects (95.5%) completed the survey via telephone rather than anonymously online. This could have introduced additional bias, as subjects may be reluctant to express dissatisfaction with care in the absence of anonymity. However, the telephone interview was not conducted by the patient's treating neurologist. Furthermore, none of the subjects who completed the survey online reported dissatisfaction with their teleneurology visit.

Given the nature of the study design, only patients who could answer the questions themselves in English or Spanish were included. This inclusion criteria may have disproportionately excluded patients with intractable epilepsy, by extension perhaps resulting in a lower rate of worsened seizure



control during the pandemic. The complexity of the public health crisis and our medical center's response, and the urgent need for details and feedback to inform our practice and teleneurology outreach, limited our ability to perform extensive questionnaire validation. We addressed this by piloting an initial questionnaire with subjects and seeking feedback on the questionnaire from a large group of practicing Bronx neurologists. We also validated patients' response to the key question about seizure control during the pandemic with their estimates of seizure quantity, although this would not account for changes in seizure severity. However, the questionnaire did not utilize standardized measures of seizure frequency or severity. Finally, epilepsy is not a static disease. There are natural fluctuations in seizure control, and likely some patients would have experienced improved or worsened seizure control irrespective of the pandemic.

## 5 | CONCLUSIONS

More than one of every six subjects in our cohort reported worsened seizure control during the peak of the COVID-19 pandemic in New York City. Increased stress in patients with frequent seizures who report stress as a common seizure precipitant likely played a large role, as did suboptimal access to care and difficulty obtaining antiseizure medications. In contrast, 7.3% of subjects reported improved seizure control. We plan a follow-up to see when or whether their seizure control returned to baseline. Patients must be able to reach their neurologists amid unprecedented circumstances. Medical personnel should work with patients and pharmacists to ensure access to medications, and we must improve delivery of epilepsy care with telemedicine.

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## CONFLICT OF INTEREST

A.S.G. is Co-Editor in Chief of *Epilepsia Open* and has received royalties for publications from Elsevier and Morgan

and Claypool publishers. S.L.M. is serving as Associate Editor of *Neurobiology of Disease* and is on the editorial board of *Brain and Development*, *Pediatric Neurology*, and *Physiological Research*. He receives from Elsevier an annual compensation for his work as Associate Editor of *Neurobiology of Disease* and royalties from two books he coedited. He has received consultant's fees from UCB and Pfizer. S.H. is serving as a consultant for Alden Health. None of the other authors has any conflict of interest to disclose.

## ETHICAL PUBLICATION STATEMENT

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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