



# The Impact of COVID-19 on Epilepsy Care: A Survey of the American Epilepsy Society Membership

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## Abstract

The COVID-19 pandemic has impacted the delivery of care to people with epilepsy (PWE) in multiple ways including limitations on in-person contact and restrictions on neurophysiological procedures. To better study the effect of the pandemic on PWE, members of the American Epilepsy Society were surveyed between April 30 and June 14, 2020. There were 366 initial responses (9% response rate) and 337 respondents remained for analysis after screening out noncompleters and those not directly involved with clinical care; the majority were physicians from the United States. About a third (30%) of respondents stated that they had patients with COVID-19 and reported no significant change in seizure frequency. Conversely, one-third of respondents reported new onset seizures in patients with COVID-19 who had no prior history of seizures. The majority of respondents felt that there were at least some barriers for PWE in receiving appropriate clinical care, neurophysiologic procedures, and elective surgery. Medication shortages were noted by approximately 30% of respondents, with no clear pattern in types of medication involved. Telehealth was overwhelmingly found to have value. Among the limitation of the survey was that it was administered at a single point in time in a rapidly changing pandemic. The survey showed that almost all respondents were affected by the pandemic in a variety of ways.

## Keywords

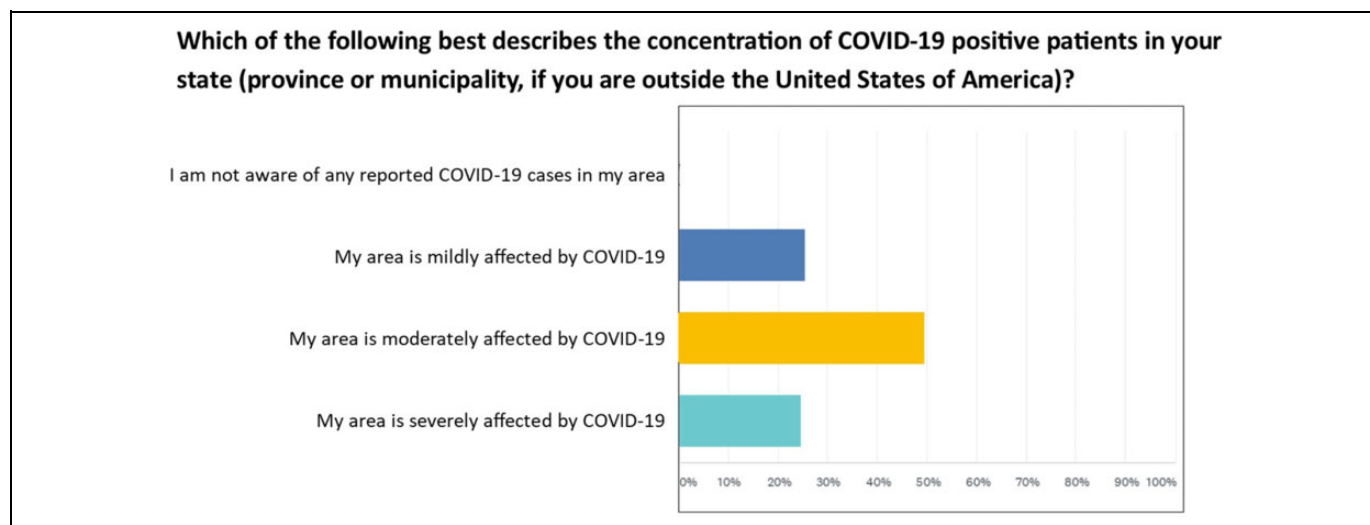
COVID-19, SARS-CoV-2, survey, epilepsy care, seizures, people with epilepsy (PWE), EEG, telehealth

The corona virus infectious disease-2019 (COVID-19) pandemic has had an exceptional impact on delivery of care to people with epilepsy (PWE). In addition to obviously impacting PWE, the pandemic has also affected epilepsy care

providers. In mid-April, 2020, the American Epilepsy Society (AES) determined that a membership survey should be conducted to better understand the effects of the COVID-19 pandemic on members and the patients they serve. The



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**Figure 1.** Concentration of COVID-19 cases.

Quantitative Practical Use-Driven Learning Survey in Epilepsy (Q-PULSE) Taskforce was charged with creating a survey that would assess how the most important aspects of epilepsy care delivery were being affected. Unlike typical Q-PULSE surveys that are sent only to National Association of Epilepsy Center directors, this survey was sent to all AES members, as it was intended to reflect broad practice experiences. The survey was sent in late April 2020, and several emails were sent to encourage members to complete it.

The survey was open April 30 to June 14, 2020. The survey was publicized by AES to members through 3 e-blasts, several *AES Connections* e-newsletter items, *AES Connect* forum, and various social media posts. The survey did not specifically screen for AES membership, and electronic publicity distribution meant that non-AES members may have been among respondents. The initial survey questions did screen out respondents who were not directly involved in clinical care. Of the 4193 average distribution for the 3 e-blasts, an average of 1448 (34%) opened each message, and a total of 434 recipients clicked through to the survey. Overall, a total of 366 members responded to the survey (response rate of 9% of the total member e-blast distribution). Of the 366 total initial respondents, 29 did not complete the survey (21 not directly involved in patient care and 8 completed only demographic questions). A total of 337 respondents completed some portion of the remaining survey questions. Because responses were not required, not all respondents completed all questions.

The AES Guidelines and Assessment Committee (GAC) was charged with analyzing the results. A volunteer group of members of the GAC and a few members of the Q-PULSE Work Group summarized the results of the survey. The results are divided into 4 parts: demographics, patient care issues, practice-related issues, and telehealth. Because of its importance in the current pandemic, telehealth questions were separated from other practice-related questions. Several questions were open ended, and the information from the survey is

summarized here. A PDF of the survey questions is provided in Online Appendix 1. It is important to appreciate that the results presented are a snapshot of member practice and not clinical guidance.

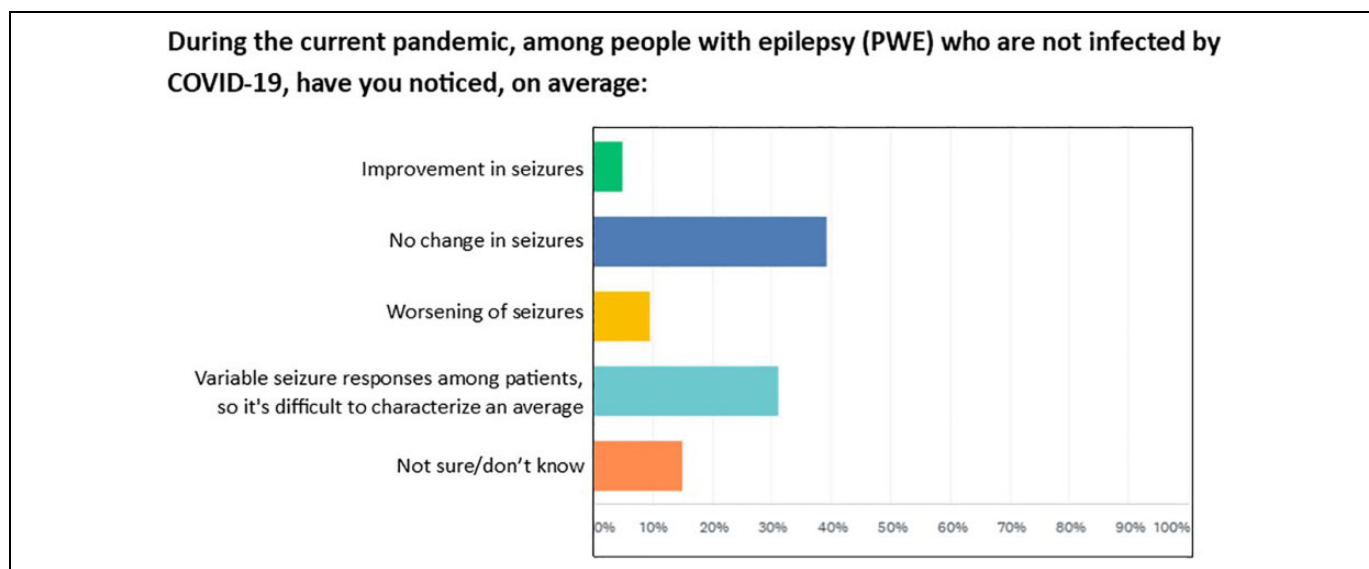
## Demographics

There were 337 respondents to the survey. The majority of respondents (79%) were physicians. Medical trainees constituted 7% of the respondents, while 5% were advanced practice providers, and 3% were electroencephalography (EEG) technologists. Most respondents were from the United States (80%), while 7% were from Europe. The rest, about 4% each, were from South America, Asia, and non-US North America. Respondents were asked how they would describe the degree of community spread of COVID-19 cases in their region using subjective terms (no reported cases, mild, moderate, severe). At the time the survey was conducted, one-half (50%) described their geographic region (American state or country) as “moderately” affected by the COVID-19 pandemic, while a quarter each described their region as “severely” or “mildly” affected. Only one respondent was not aware of COVID-19 cases in their area (Figure 1).

## Impact on Patient Care

### Seizures and COVID-19

About a third (30%) of the survey respondents reported a suspected cause for new onset seizures in COVID-19 patients. Most often the mechanism thought to be responsible for the seizures was lowered seizure threshold with preexisting risk factors. Some respondents suspected viral invasion of the central nervous system (CNS) and injury from SARS-CoV-2. Rarely, seizures were attributed to cardiac arrest or stroke that occurred during the illness. Most survey respondents (63%) indicated that the new-onset seizures were mostly focal-onset



**Figure 2.** Effects of the COVID-19 pandemic on PWE.

with or without evolution to bilateral tonic-clonic seizures. Other respondents identified seizures as generalized, electrographic only or unclassifiable almost equally.

One-third of respondents reported that they had PWE in their practice that had been diagnosed with COVID-19. A majority of these PWE had no change in seizure frequency. About 17% of the respondents noted worsening, while none noted an improvement in seizures in PWE with COVID-19.

In PWE who had not been infected with SARS-CoV-2, most respondents did not see a change in seizure frequency in their patients. However, 10% of respondents noted a worsening in seizure frequency, while 5% noted an improvement (Figure 2). Worsening of seizure frequency was attributed to increased stress, sleep deprivation, and reduced access to pharmacies and medications. However, when survey participants were specifically asked if PWE were reporting increased seizures as a result of emotional stress, more than 80% of respondents either disagreed or were neutral or unsure. Conversely, improved seizure control was attributed to better sleep and medication adherence.

### Epilepsy Clinical Care

Concerns have been raised about the quality of care provided to PWE during the COVID-19 pandemic. Forty-three percent of the survey respondents thought that PWE received the expected standard of care during the pandemic, while 34% thought that care was compromised. The remaining 17% were either neutral or unsure.

The majority of respondents felt that there were at least some barriers for PWE in getting appropriate clinical care, testing (including EEG and video EEG monitoring) and elective surgery. The reasons for these barriers were thought to include loss of employment and financial stress, lack of access to health care service due to closure, transportation issues, lack of access to technology for telehealth, and reluctance to seek

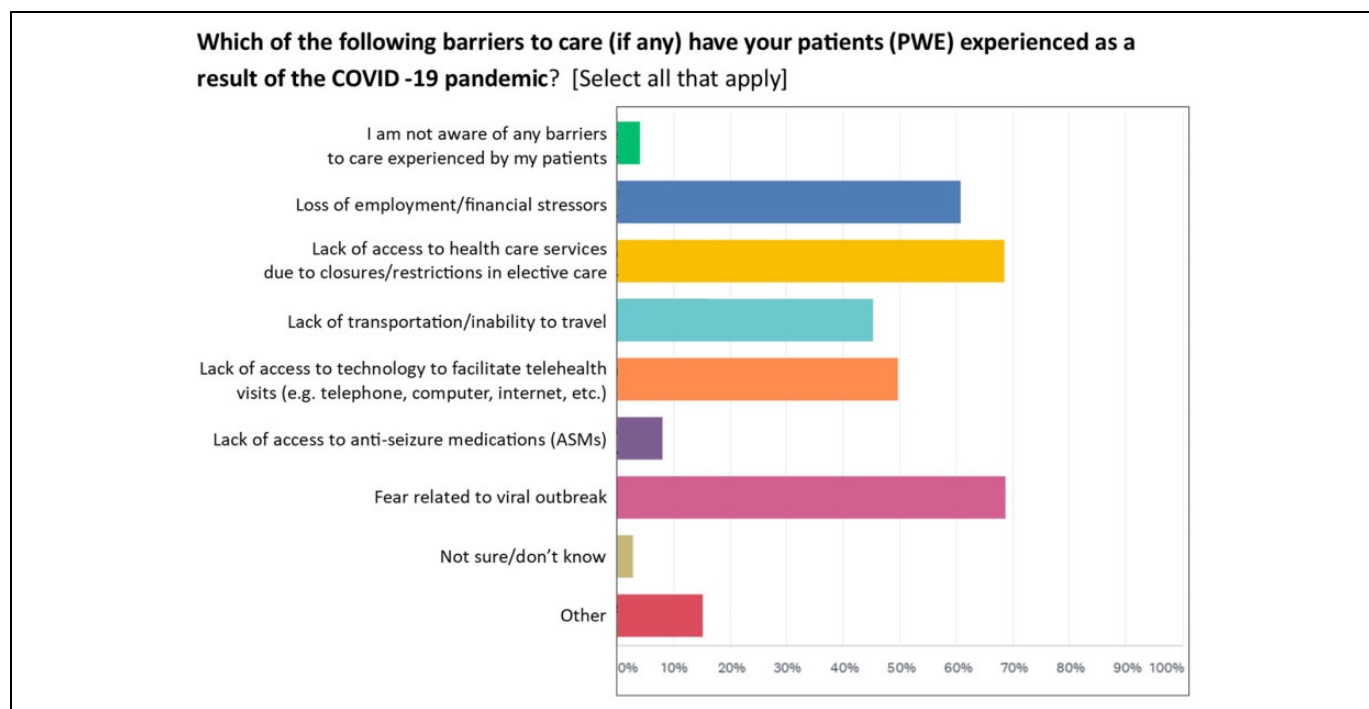
care due to fear of viral outbreak (Figure 3). Other barriers identified by some respondents were reduced access to specialty pharmacy services for patients with severe epilepsies, loss of insurance leading to lack of medication coverage, loss of behavioral health services, and increase in stress, anxiety, and depression due to the pandemic. Respondents noted that overall, the COVID-19 pandemic has not resulted in a significant change in phone calls from patients to clinics, although both increased and decreased calls were reported in some instances.

### Impact on Clinical Practice

#### Barriers to Providing Care

A range of barriers were reported in providing care during the pandemic. Most frequently noted were limited access to in-person visits and nonemergency testing reported by 74% and 66% of respondents, respectively. Provider fear related to the outbreak and concern for their own well-being was reported by nearly 30%, while lack of personal protective equipment (PPE) and financial considerations were reported by 25% of respondents. Technological problems for telehealth visits were noted in only 15% of respondents. Only 7% of respondents experienced no barriers in providing patient care during the pandemic. One respondent noted that between the pandemic and Centers for Medicare and Medicaid Services (CMS) cutbacks on EEG reimbursement, continuing practice appeared difficult.

Respondents also cited the following additional practice-related barriers to providing care: prioritization of COVID over nonurgent care; suspensions of epilepsy monitoring units (EMUs), vagus nerve stimulator implantations, and presurgical evaluation and surgery; reopening logistics; staff cuts; and clinic staffing (eg, childcare challenges and fear of exposure to COVID). Regarding when respondents expected to return services to pre-COVID-19 levels, the answers formed a normally distributed Bell-shaped curve between now and never,



**Figure 3.** Barriers to care of PWE during COVID-19 pandemic.

centered at approximately 6 months. Only 9% of respondents were not sure. Approximately 5% did not feel their practice would ever return to normal.

### Neurophysiologic Evaluations

About half of respondents (47%) reported that EEGs were discouraged for patients admitted to the hospital with COVID-19 or those suspected of having the infection. Even without restrictions, nearly a quarter (22%) reported they were doing fewer studies than usual (Figure 4). About 9% responded they were no longer doing continuous video-EEG monitoring. In the write in comments, many respondents noted that their EMUs had closed. Very few respondents (2%) reported that they were doing more EEGs than usual; of this group, 5 were from institutions where there were no restrictions for performing EEGs during the COVID-19 pandemic.

### Medication Interactions or Shortages

Almost no respondents had seen unusual interactions between anti-seizure medications (ASM) and medications used to treat COVID-19. Medications shortages were noted by approximately 44% of respondents (Figure 5). In write-in comments, the most frequently noted shortages were of extended release levetiracetam and midazolam, and other shortages of several IV benzodiazepines were noted by some respondents. However, it appears some of these shortages existed from prior to the pandemic. By and large, there appeared to be no consistent pattern of shortages of conventional ASMs directly attributable to the pandemic. The majority of shortage reports originated

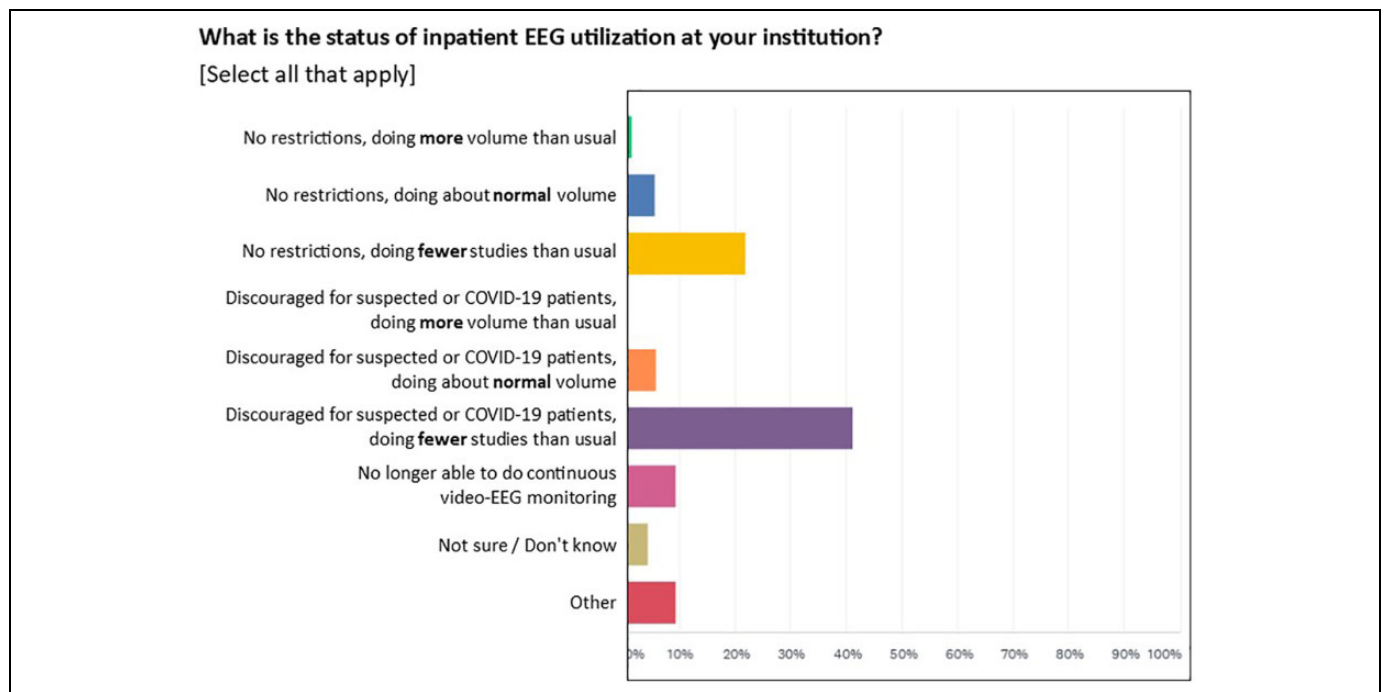
from patients; IV anesthetic shortages were reported by inpatient pharmacies.

### Impact on Trainees

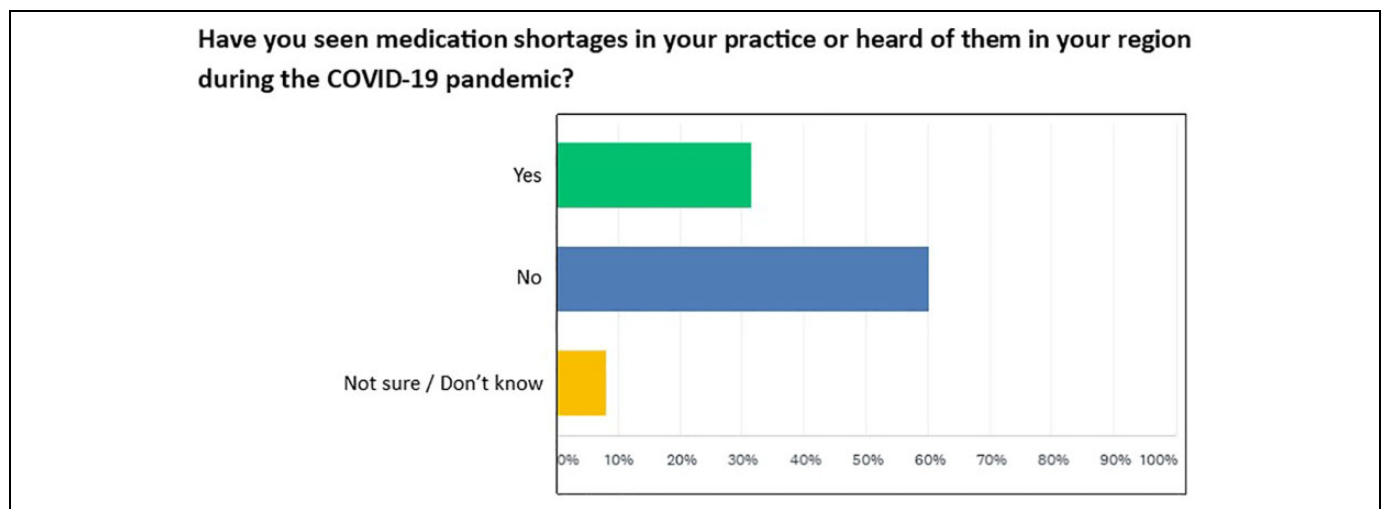
Trainees (residents and fellows) responded in low numbers and noted that the pandemic has harmed their educational experience. They cited reduced patient volumes and canceled clinics as responsible factors. Furthermore, the cancelling of interprofessional conferences and educational meetings limited learning and networking opportunities outside the home institution as well as the opportunity to present academic work.

### Telehealth

Nearly all respondents (90%) indicated a willingness to use telehealth in some capacity; only 2% said that they had not used telehealth and did not plan to use it (Figure 6). Many respondents had experienced benefits of telehealth over in-person clinic encounters. The benefits included improved access, decreased no-show rates, observations of the home environment, participation of families/caregivers, general efficiency of the visits, flexibility for patients and providers, enhanced integration with multidisciplinary teams, and increased access to psychosocial care providers. Respondents also reported that their recent telemedicine experience demonstrates that much of pertinent examinations for epilepsy care, especially for follow-up visits, can be done with telehealth (eg, mental status, gait, coordination, cranial nerves, nystagmus, and ataxia evaluation). Problems identified by respondents



**Figure 4.** Inpatient EEG utilization during COVID-19 pandemic.



**Figure 5.** Medication shortages during COVID-19 pandemic.

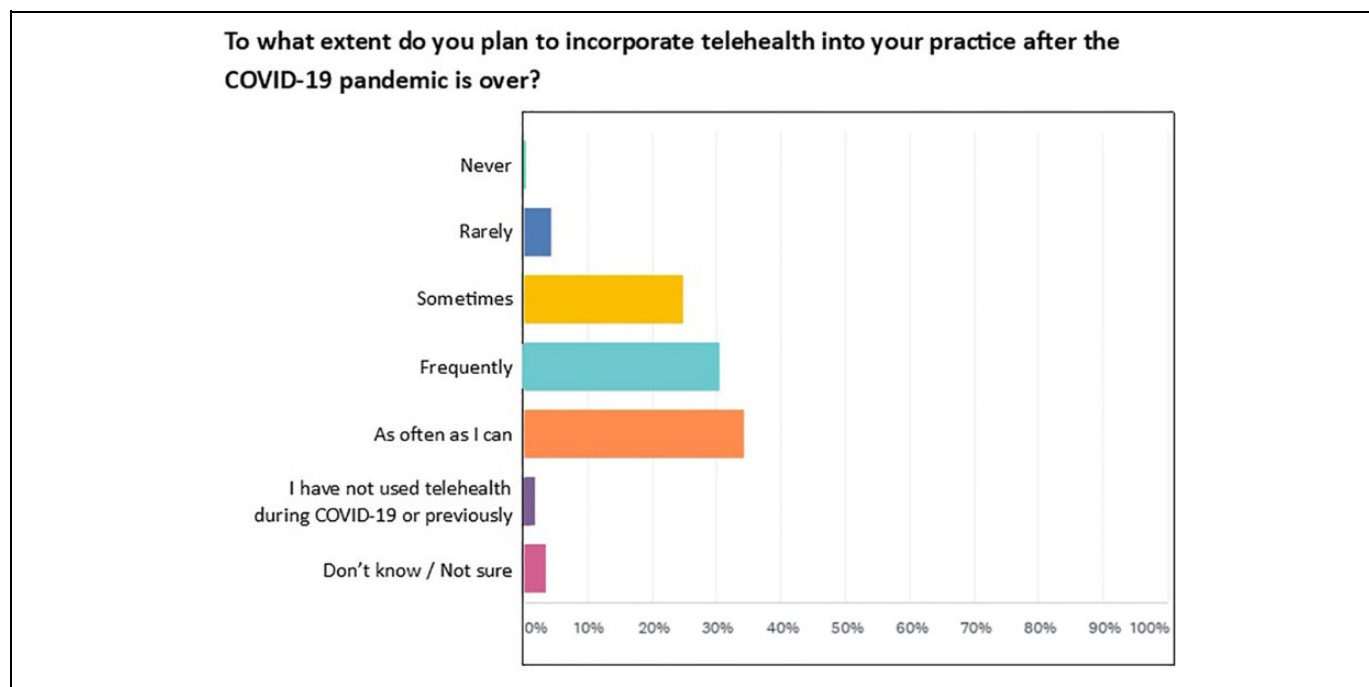
included technical difficulties, lack of physical contact, and inability to perform diagnostic monitoring and laboratory tests.

Certain patient populations emerged as likely to particularly benefit from telehealth. This included patients living far away from clinics, needing to take extended time off from work to attend clinic visits, with disabilities and requiring transportation, or living in extended care facilities. This survey also suggested that the most vulnerable patients are negatively affected by the use of telehealth services, in that the lack of internet access and/or video-capable device has resulted in

suboptimal interaction or necessitated an in-person visits to the clinic.

The Veterans Administration's Epilepsy Centers of Excellence longstanding experience with telehealth was cited as a model for utilization of telemedicine for providing direct patient care, reading EEG studies remotely or reviewing them for quality assurance, and provider-to-provider consultation in treating epilepsy patients.

The survey respondents emphasized concerns regarding continued reimbursement for telehealth visits. Many



**Figure 6.** Telehealth during COVID-19 pandemic.

respondents wanted advocacy for continued reimbursement parity for telemedicine visits compared to in-person visits.

## Discussion

On March 11, 2020, concerned by the severity of the infection and the significant level of spread, the World Health Organization classified COVID-19 as a pandemic.<sup>1</sup> One week later, the US CMS released guidance recommending that elective surgeries and nonessential medical procedures be postponed to preserve PPE, reduce exposure among health care workers, and allow for the redeployment of medical personnel to provide care where gaps existed.<sup>2</sup> This guidance resulted in an unprecedented change in health care delivery for all patients. People with epilepsy have a chronic disease, often associated with other comorbidities and daily medication use, making them particularly vulnerable to changes in health care delivery induced by the pandemic. Moreover, medical practitioners suddenly found themselves confronted with finding innovative methods of delivering medical care, while worrying about their personal health. It was against this backdrop that the AES commissioned this survey of its membership. Importantly, this survey was not sent to PWE, rather it focused on AES members perspectives during the pandemic.

### Seizures and COVID-19

Initially thought to be mainly a respiratory infection, it is now clear that COVID-19 is associated with neurological involvement in more than 30% of patients, with approximately 25% having symptoms indicating CNS dysfunction. Fortunately, the incidence of seizures appears to be low (0.5%).<sup>3</sup> Although there

are case reports of seizures at onset in both adults and children, new-onset seizures and status epilepticus (SE) are rarely described. In a recent multicenter, retrospective study of 304 people with no known history of epilepsy in China, neither acute symptomatic seizures nor SE was observed.<sup>4</sup> Two people had seizure-like symptoms during hospitalization that were thought to be related to acute stress reaction and hypocalcemia. There was no evidence suggesting an additional risk of acute symptomatic seizures in people with COVID-19. About a third (30%) of respondents in the current survey reported seeing COVID-19 patients with new-onset seizures. This high rate, which is much higher than we might expect given the reported rate of new-onset seizures in the literature (0.5%), is likely reflective of the population surveyed, namely epilepsy specialists.<sup>3</sup>

A number of mechanisms of neuropathogenesis related to COVID-19 have been described, including manifestations of systemic disease including hypoxia, metabolic derangements, and multi-organ failure; direct invasion of the nervous system (meningitis/encephalitis); and a postinfection immune-mediated process.<sup>5,6</sup> All of these may lead to seizures, but the specific contribution of each mechanism is unclear, and in some cases the cause may be multifactorial. Meningoencephalitis associated with COVID 19 with transient seizures has been described in one patient.<sup>7</sup> The responses in the AES survey reflected similar uncertainty of possible mechanisms causing seizures.

There are very few data regarding the type of new-onset seizures seen in patients with COVID-19 in the literature. There is a single case report of focal SE as a presenting manifestation in a patient with underlying postencephalitic



epilepsy.<sup>8</sup> A small case series of 7 patients with COVID-19 presenting with seizures, of which 4 had new-onset seizures, has been reported.<sup>9</sup> A patient with COVID-19 related meningoencephalitis was reported to have generalized seizures lasting about a minute.<sup>7</sup> One EEG-based case series demonstrates abnormalities seen in encephalopathic patients with COVID-19, including generalized slowing, generalized epileptiform discharges and focal seizures, although many of the patients in the series had preexisting epilepsy.<sup>10</sup> In this study, there were 2 patients with focal seizures, 1 was new onset and 1 was in a PWE. Additionally, in this study several patients had generalized periodic discharges of triphasic morphology. Other patients with COVID-19 related new onset seizures and SE have also been described.<sup>11,12</sup>

Respondents in the current survey did not notice an increase in susceptibility of PWE to COVID-19. This is supported by a consensus statement which finds no increased risk of acquiring COVID-19 in most PWE.<sup>13</sup> Exceptions include PWE who are being treated with immunosuppressant medications or those particularly sensitive to fever. However, a recent study that reported on EEG findings in 8 patients with COVID-19 related neurologic problems found 5 (63%) had a history of epilepsy.<sup>10</sup> These authors raised the concern that PWE may be at increased risk developing neurologic manifestations if they acquire COVID-19.

### Obtaining and Delivering Epilepsy Care

Concerns were raised in this survey that PWE could not get the usual care for their medical issues during the pandemic. Many of these issues were due to new financial and logistical constraints for patients during the pandemic. No comparable data regarding these issues are currently available in the literature.

Care was also affected due to limitations imposed by hospitals, clinics, and medical practices. Institutions across the United States began to restrict or cancel admissions to epilepsy monitoring units (which are typically elective in nature). In addition, performing both inpatient and outpatient EEGs was significantly reduced due to the close contact of the EEG technologist with patients and to reduce depletion of PPE.<sup>14</sup> Telemedicine visits were encouraged for the care of PWE during the pandemic wherever possible to reduce the risk for PWE and their family for being exposed to the infection in health care facilities.<sup>13</sup>

The effect of reduced access to in-person epilepsy care and neurodiagnostic procedures has not been clearly studied. An Italian study that surveyed people with and without epilepsy found that those with epilepsy reported a significantly increased risk of seizures and difficulties in obtaining follow-up clinic appointments.<sup>15</sup>

Shortage of ASM has not been a major concern during the current pandemic. Most respondents did not notice lack of availability of ASM, with the exception of long acting levetiracetam. However, the Food and Drug Administration has reported intermittent shortages of medications used to treat acute seizure, such as midazolam and propofol, during the

pandemic.<sup>16</sup> This is likely due to use of these medications in critically ill patients, not necessarily those with seizures. There is also little evidence of the effects of various medications used to treat COVID-19 on seizures and ASM. In response, the AES Treatments Committee has created a resource, *Managing Patients with Epilepsy during COVID-19: Pharmacotherapy-related Recommendations*.<sup>17</sup> American Epilepsy Society has created a COVID-19 and Epilepsy web portal with information relating to various aspect to care delivery.<sup>18</sup> Interestingly, despite almost all participants being impacted in some way by COVID-19, only 41% of respondents to the survey were aware of these resources, and 38% had used them. A campaign to increase awareness of this resource may help members.

### Telehealth

The value of telehealth in neurology has been recognized well before the COVID-19 pandemic, with particularly successful implementation in stroke care.<sup>19,20</sup> The feasibility of telehealth in epilepsy care, including delivery of complex care to patients with refractory epilepsy, has similarly been demonstrated, with comparable outcome and high patient satisfaction.<sup>13,21-23</sup> The lack of commensurate reimbursement has historically been the barrier to greater adoption.<sup>24</sup>

Several early studies have examined the effect of transition to telehealth during the COVID-19 pandemic. A recent survey of child neurologists conducting telehealth encounters, in which epilepsy was somewhat overrepresented, revealed >90% satisfactory encounters despite 40% reporting technical challenges. Most (86%) reported intending to pursue telehealth in future encounters.<sup>25</sup> An international survey of pediatric neurologists treating children with epilepsy revealed that about 25% of practitioners were seeing outpatients exclusively with telehealth and 95% were seeing at least some patients by telehealth.<sup>26</sup> A US-based single hospital system evaluation revealed that 67% of outpatient visits were completed via telehealth, 32% with phone visits, and only 1% of visits were in-person clinic encounters.<sup>27</sup>

Similar to previous studies, the respondents in the current survey overwhelmingly found value in telehealth. Many benefits were noted, including efficiency of the clinic visits. Respondents even noted that many of the examination elements that they routinely perform, such as mental status and gait evaluations, could be done via telehealth. One shortcoming that was mentioned was the lack of diagnostic monitoring and laboratory testing. However, a recent randomized trial revealed little benefit in monitoring serum levels of modern ASMs.<sup>28</sup>

Whereas previous efforts in telehealth in epilepsy care have focused on the delivery of care to resource-limited or poorly accessible regions, the current situation has affected health care delivery across all socioeconomic spectra. Unfortunately, the most socioeconomically vulnerable patients have difficulty in getting telehealth services as well due to lack of access to technology. This is an area that should be promptly and actively addressed, particularly since the near-term outlook for the pandemic remains extremely concerning.



### Key takeaways

- The majority of respondents of this survey were physicians in the US from areas moderately or severely affected by COVID-19 and who care for both inpatients and outpatients.
- One-third of respondents had encountered patients with COVID-19 who had new-onset seizures, likely from lowered seizure threshold with pre-existing risk factors and less often due to perceived direct viral invasion or neuronal injury. These seizures were more likely to be focal (with or without evolution to bilateral tonic-clonic seizures) than generalized.
- Approximately one-third of respondents had PWE in their practice who developed COVID-19. In most of these PWE, seizure frequency remained unchanged or showed a variable response; increase was noted by approximately 16% of the respondents.
- PWE without SARS-CoV-2 infection generally showed no change in seizure frequency but a small number had worsening or improvement. Worsening was rarely thought to be related to emotional stress.
- Overall, the COVID-19 pandemic has not resulted in a significant change in phone calls from patients to clinics, although both increased and decreased calls have been reported in some instances.
- In the experience of about one-third of survey respondents, the COVID-19 pandemic may have resulted in less than the expected delivery of standard of care particularly in terms of clinical evaluation, testing and elective surgery due to financial, technological, transport and access barriers. However, forty-three percent of providers reported that patients were receiving the expected standard of care.
- The EEG volume has substantially decreased during the pandemic. In concert with the recent CMS cutbacks on EEG reimbursement, this has created financial difficulty for many respondents, with a small number anticipating not being able to continue practice.
- No significant systematic shortages in ASMs were noted, aside from possible shortages of levetiracetam and IV benzodiazepines, especially midazolam.
- Most respondents experienced some forms of barriers to providing care, most relating to access to in-person visits and testing. About one-quarter felt that lack of PPE was an additional barrier to providing care.
- Most respondents seemed to have an idea when their practices were going to return to pre-COVID-19 levels, but there was little agreement as to exactly when this would be.
- Most respondents have successfully adopted telehealth for epilepsy care, many cited its advantages for providing health care to patients with epilepsy, and most plan to utilize it even after the pandemic. There is concern for continued regulatory and payer support of telehealth and adequate reimbursement for this practice.
- The COVID-19 pandemic may have impacted epilepsy education for medical trainees.

**Figure 7.** Key takeaways.

An important consideration about telehealth raised by respondents to the survey is continued reimbursement. While there was overwhelming recognition of the value of telehealth and many respondents saw the value in continuing it long term, they expressed concern that reimbursement models changed after the pandemic, they would be unable to continue it.

Encouragingly, professional societies are collaborating in a variety of way to advocate for telehealth for PWE as well as others that greatly benefit from this method of care.<sup>29</sup>

### Limitations

There are several limitations inherent in this type of study including the potential for recall, sample, and responder biases. Furthermore, the survey asks clinicians their impressions of the impact of COVID-19 on PWE in their practice, not patients themselves. In addition, the COVID-19 pandemic has been a rapidly evolving phenomenon and this survey represents a snapshot in time early in the pandemic. Responses might change if members were surveyed later in the pandemic or even postpandemic.

### Conclusions

This survey of AES membership conducted in May and June 2020 found that almost all respondents had been impacted in some way by the COVID-19 pandemic. Key “Takeaways” are summarized in Figure 7. Most health care providers did not perceive that PWE have experienced an increase in seizure frequency during the pandemic or as a result of COVID-19 infection. There are many barriers to care that have occurred; however, the pandemic has also forced innovations, such as in telehealth, that have led to enhancements in care delivery. The survey identified areas in which to continue to provide services to AES members so that they may more effectively deliver the best possible care to PWE.

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## Supplemental Material

Supplemental material for this article is available online.

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