American Epilepsy Society (AES) Survey

*Impact of COVID-19 Pandemic on Epilepsy Care*

Summary of Results

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### Authors

AES Guidelines and Assessment Committee members Dara V.F. Albert, DO, MEd; Rohit R. Das, MD, MPH; Jayant N. Acharya, MD, DM; Jong Woo Lee, MD, PhD; Q-PULSE members John R. Pollard, MD; and Vineet Punia, MD, MS; Joy A. Keller, MS, RD, MSLIS, AES Staff; and Aatif M. Husain, MD, Guidelines and Assessment Committee Chair

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I. Introduction

The Corona Virus Disease (COVID) -19 pandemic has had an exceptional impact on delivery of care to persons with epilepsy (PWE). In addition to obviously impacting PWE, the pandemic has also affected epilepsy care providers. In mid-April, the AES 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, this survey was intended to reflect broad practice experiences. The survey was sent to all AES members in late April, with several follow-up emails sent to encourage completion.

The survey was open April 30 - June 14, 2020 and, while not restricted to AES members, was publicized through member e-blasts, AES Connections e-newsletter items, AES Connect forum, and various social media posts. Of the 4,193 average distribution for the e-blasts, an average of 1,448 (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 initial respondents, 29 did not complete the survey (21 were 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.

The AES Guidelines and Assessment Committee (GAC) analyzed the results. The results will be published in Epilepsy Currents, and a synopsis is provided here. The results are divided into three parts: demographics, patient care, practice-related issues, and telehealth. Several questions were open ended, and the information from the survey is summarized briefly here, with a more detailed analysis of results pending publication. Key Takeaways are also provided for an “at-a-glance” summary.

II. Demographics and COVID-19 Impact

- The vast majority of individuals who answered the survey described themselves as physicians (79%). Less often the respondents were medical trainees (residents or fellows; 7%), advanced practice providers (5%) and EEG technologists (3%). The rest of the group was made up of social workers, psychologists, nurses and scientists.
- The plurality of respondents (86%) saw both inpatients and outpatients.
- Most respondents were from the United States (80%) and Europe (7%), followed almost equally by South America, North America excluding the US and Asia (4%).
- When asked to describe the concentration of COVID-19 cases in subjective terms in their region (state if from the US), 50% of respondents stated that their area was “moderately affected.” Twenty-five percent each stated that their areas were “severely affected” and “mildly affected.” (Figure 1).
III. Patient Care

A. COVID, Patients with Epilepsy, and Seizures

- Only about 30% of 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 pre-existing risk factors. Some respondents suspected viral invasion/injury from SARS-CoV-2. Rarely other causes of seizures were noted, such as post-cardiac arrest and post-stroke seizures.

- Regarding the type of new-onset seizures in patients with COVID-19, approximately 63% of respondents reported focal-onset seizures with or without evolution to bilateral tonic-clonic seizures. The remaining were more or less evenly distributed among generalized, electrographic only, and those with insufficient data for classification.

- Only a third of respondents reported seeing PWE in their practice diagnosed with COVID-19.

- Regarding changes in seizure frequency in PWE infected with COVID, the majority of respondents reported no change or variable, uncertain responses, while 17% reported worsening of seizures. No one reported improvement in seizure frequency.

- Among PWE not infected by SARS-CoV-2, the majority of respondents reported no change in seizure frequency or variable, uncertain responses. About 10% reported worsening of seizures, while 5% noted improvement (Figure 2). Hypotheses offered for worsening included increased stress, sleep deprivation, and reduced access to pharmacies or medications. When survey participants were 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.
B. Standard of Care, Patient Care Needs, and Barriers to Care Experienced by Patients

- About 40% of respondents reported no change or were unsure about a change in the frequency of phone calls to clinic staff. The rest were split more or less evenly among increase and decrease.
- Slightly more (43% vs. 34%) respondents agreed than disagreed that PWE received the expected standard of care during the pandemic, with the remaining 17% being neutral or unsure.
- The majority of respondents felt that there were some barriers to care for PWE in terms of clinical evaluation, testing including EEGs and video-EEG monitoring, and elective surgery. Reasons for the barriers were variable and included loss of employment/financial stress, lack of access to health care services due to closures, transportation issues, lack of access to technology, and fear related to viral outbreak (Figure 3).
- Additional barriers to care for patients noted by respondents included reduced access to special pharmacy services for patients with severe epilepsy and loss of insurance, with resulting impact on coverage and continuity of medications and behavioral health services.
- Independent of insurance coverage, difficulty accessing behavioral health care, especially that offered via telehealth, was highlighted as a particular concern for patients with epilepsy in light of pandemic-related rises in stress, anxiety, and depression.
IV. Practice-Related Issues

A. 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 non-emergency testing reported by 74% and 66% of respondents, respectively. Provider fear related to the outbreak 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 visit were noted by 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.

- In open ended responses, respondents cited the following additional practice-related barriers to providing care: prioritization of COVID over non-urgent care; suspensions of Epilepsy Monitoring Units (EMUs), VNS implantations, and pre-surgical evaluation and surgery; reopening logistics; staff cuts; and clinic staffing (e.g., 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, centered at ~6 months. Only 9% were not sure. Approximately 5% did not feel their practice would ever return to normal.

B. Impact on Neurophysiologic Evaluations

• Approximately 47% of respondents reported that inpatient EEGs were discouraged for COVID-19 patients or those suspected of having the infection. Even where there were no restrictions, 22% of responders found they were doing fewer studies than usual (Figure 4). Significantly, about 9% responded they were no longer doing continuous video-EEG monitoring. Many noted in write-in comments that their EMU had closed. Only 7 respondents (about 2%) reported that they were doing more EEGs than usual; of this group 5 came from institutions where there were no restrictions for EEG during the COVID-19 pandemic.

Figure 4: Inpatient EEG utilization
C. COVID and Medication Interactions or Shortages

- Almost no respondents reported seeing any unusual interactions between antiseizure medications (ASM) and medications used to treat COVID-19. Additional information regarding pharmacotherapy for PWE has been compiled since the survey and can be found among [AES COVID Treatments resources](#) and particularly in [Managing Patients with Epilepsy during COVID-19 - Pharmacotherapy-related Recommendations](#).

- Approximately 44% of those responding “Yes” or “No” noted medications shortages (Figure 5). The most frequently noted shortages were of extended release levetiracetam and midazolam, and some respondents noted other shortages of several IV benzodiazepines. However, it appears some of these shortages persisted 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 reported shortages originated from patients; IV anesthetic shortages were reported by inpatient pharmacies.

**Figure 5: Medication shortages**

![Medication shortages chart]

D. Training Impact

- The few resident and fellow respondents noted that the pandemic has harmed their educational experience and cited reduced patient volumes and cancelled clinics as factors.

- Cancellations of professional and educational meetings limited learning and networking and opportunities to present academic work.
E. Telehealth

- Almost 90% of respondents indicated they would use telehealth sometimes or frequently, with 66% stating they would use it frequently/as frequently as possible (Figure 6). Only 2% of respondents had never used telehealth or were not planning to use it. Many respondents expressed positive views about telehealth, noticed greater patient satisfaction, and/or noted increased visit adherence.

- In an open-ended question about provider experiences with the impact of COVID-19 on epilepsy care, 56% of the 86 respondents mentioned telehealth.

- Respondents reported that recent telehealth experience demonstrates that much of pertinent examinations for epilepsy care, especially for follow-up visits, can be done by telehealth (e.g., mental status, gait, coordination, cranial nerves, nystagmus, ataxia).

- While acknowledging some limitations (technical issues for patients and/or providers, limits on diagnostic and other testing, less personal interaction), comments overwhelmingly focused on telehealth advantages for PWE (e.g., follow-up care continuity without risk of COVID infection, time efficiencies and flexibility for patients and providers, closer contact with patients and families/caregivers, enhanced integration with multi-disciplinary care teams, and ability to involve primary care providers and/or psychosocial providers in consults).

- Examples of patient populations cited as particularly benefitting from telehealth services included those who: live far from a clinic, need to take extended time off work for in-person clinic visits, have disabilities or special needs for whom transportation or logistics are a challenge, do not drive or depend on others for transportation, and/or reside in extended care facilities.

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

- There was concern regarding continued reimbursement for telehealth. The need to advocate for continuity of telehealth services coverage and related appropriate reimbursement after the pandemic was emphasized by numerous respondents.
V. 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.
- About a third (30%) 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 reported PWE in their practice who developed COVID-19. In most of the PWE seizure frequency remained unchanged or showed a variable response; an increase was reported by approximately 16% of 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, 43% 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.

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