

Epilepsy care during the COVID-19 pandemic

J Helen Cross¹, Churl-Su Kwon², Ali Akbar Asadi-Pooya³, Ganna Balagura⁴, Patricia Gómez-Iglesias⁵, Alla Guekht⁶, Julie Hall⁷, Akio Ikeda⁸, Nirmeen A. Kishk⁹, Peter Murphy¹⁰, Najib Kissani¹¹, Yahya Naji¹¹, Emilio Perucca¹², Juan Carlos Pérez-Poveda¹³, Emmanuel O. Sanya¹⁴, Eugen Trinká¹⁵, Dong Zhou¹⁶, Samuel Wiebe¹⁷ and Nathalie Jette² on behalf of the ILAE Task Forces on COVID-19 and Telemedicine

1. Programme of Developmental Neurosciences, UCL NIHR BRC Great Ormond Street Institute of Child Health, Great Ormond Street Hospital for Children, London and Young Epilepsy Lingfield, UK
2. Division of Health Outcomes and Knowledge Translation Research, Department of Neurology, Icahn School of Medicine at Mount Sinai, New York, NY 10029
3. Epilepsy Research Center, Shiraz University of Medical Sciences, Shiraz, Iran. Jefferson Comprehensive Epilepsy Center, Department of Neurology, Thomas Jefferson University, Philadelphia, USA.
4. Department of Neurosciences, Rehabilitation, Ophthalmology, Genetics, and Maternal and Child Health, University of Genoa, and Pediatric Neurology and Muscular Diseases Unit, IRCCS 'G. Gaslini' Institute, Genoa, Italy.
5. Epilepsy Unit. Department of Neurology. Hospital Clínico San Carlos, Health Research Institute "San Carlos" (IdISCC), Universidad Complutense de Madrid, Madrid, Spain. ORCID: 0000-0002-4759-6943
6. Moscow Research and Clinical Center for Neuropsychiatry, Moscow, Russia and Department of Neurology, Neurosurgery and Medical Genetics, Russian National Research Medical University, Moscow, Russia.
7. Executive Director, International League Against Epilepsy
8. Department of Epilepsy, Movement Disorders and Physiology, Kyoto University Graduate School of Medicine, Kyoto, Japan
9. Neurology Department, Faculty of Medicine, Cairo University, Egypt
10. Epilepsy Ireland, Dublin, Ireland
11. Neuroscience Research Laboratory, Marrakech Medical School, University Cadi Ayyad, and Neurology Department, University Teaching Hospital Mohammed VI, Marrakesh, Morocco.
12. Division of Clinical and Experimental Pharmacology, Department of Internal Medicine and Therapeutics, University of Pavia, Pavia and IRCCS Mondino Foundation (and member of the ERN EpiCARE), Pavia, Italy
13. Neuroscience Department, Faculty of Medicine, Xavierian University, and Hospital Universitario San Ignacio, Bogotá D. C., Colombia.
14. Neurology division, Medicine Department, University of Ilorin Teaching Hospital, Kwara State, Nigeria
15. Department of Neurology, Christian-Doppler University Hospital, Paracelsus Medical University, Centre for Cognitive Neuroscience, Salzburg, Austria; & Neuroscience Institute Christian-Doppler University Hospital, Paracelsus Medical University, Centre for Cognitive Neuroscience, Salzburg, Austria & Institute of Public Health, Medical Decision-Making and HTA, UMIT, Private University for Health Sciences, Medical Informatics and Technology, Hall in Tyrol, Austria

16. Department of Neurology, West China Hospital, Sichuan University, Chengdu, Sichuan, China. 610041
17. Departments of Clinical Neurosciences and Community Health Sciences, Cumming School of Medicine, University of Calgary, Calgary, Canada.

Corresponding author

Professor J Helen Cross
The Prince of Wales's Chair of Childhood Epilepsy
UCL Great Ormond Street Institute of Child Health
30 Guilford Street
London WC1N 1EH
Email:h.cross@ucl.ac.uk
Phone 44 207 905 2981

Abstract

The COVID-19 pandemic has affected care of all patients around the world. The International League Against Epilepsy (ILAE) COVID-19 and Telemedicine Task Forces examined, through surveys to people with epilepsy (PWE), caregivers and healthcare professionals, how the pandemic has affected the well-being, care and services for people with epilepsy.

The ILAE included a link on their website whereby PWE and/or their caregivers could fill out a survey (in 11 languages) about the impact of the COVID-19 pandemic, including access to health services and impact on mental health, including the 6-item Kessler Psychological Distress Scale. An anonymous link was also provided whereby healthcare providers could report cases of new onset seizures or an exacerbation of seizures in the context of COVID-19. Finally, a separate questionnaire aimed to explore the utilisation of telehealth by healthcare professionals since the pandemic began was available on the ILAE website and also disseminated to its members.

17 case reports were received; data were limited and therefore no firm conclusions could be drawn. Of 590 respondents to the well-being survey (422 PWE, 166 caregivers) 22.8% PWE and 27.5% caregivers reported an increase in seizure frequency, with difficulty in accessing medication and healthcare professionals reported as barriers to care. Of all respondents, 57.1% PWE and 21.5% caregivers had severe psychological distress (k score >13), which was significantly higher amongst PWE than caregivers ($p < 0.01$). An increase in telemedicine use during the COVID-19 pandemic was reported by healthcare professionals, with 40% consultations conducted by this method. Although 74.9% of healthcare providers thought that this impacted positively, barriers to care were also identified. As we move forward, there is a need to ensure ongoing support and care for PWE to prevent a parallel pandemic of unmet healthcare needs.

Key words: COVID-19, people with epilepsy, psychological distress, telemedicine,

1. Introduction

The COVID-19 pandemic has affected everyone around the world, not least through pressure on healthcare systems and delivery of care. The initial wave and consequent lockdowns led to the cancellation of routine investigations and elective interventions, and many healthcare providers had to move to alternative models of care delivery.

First reported in China, COVID-19 is caused by the novel virus severe acute respiratory syndrome (SARS)- coronavirus-2 (CoV2). SARS-CoV2 infection is associated with a respiratory illness of varying severity, from asymptomatic to respiratory distress syndrome to multiorgan failure with a hyper-coagulable and/or hyper-inflammatory syndrome associated with high mortality. Tens of millions of cases of COVID-19 have been confirmed globally, with millions of resultant deaths worldwide.¹ Concerns were raised as to who may be more susceptible to severe disease. Several risk factors have been identified, including older age, male sex, certain ethnicities, and various comorbidities (e.g. diabetes, obesity, cardiovascular disease, kidney disease, cancer, chronic respiratory disease).^{2,3} Furthermore, in the midst of the pressure on healthcare systems, there is evidence that healthcare delivery has been compromised for many patients across a number of disciplines particularly for those with a history of stroke, myocardial infarction, oncological conditions and psychiatric disorders.⁴⁻⁸

As the pandemic hit and services shut down, healthcare professionals attempted to address the needs of people with epilepsy⁹⁻¹⁴ with a specific focus on telehealth and remote working. Although in some areas positive outcomes were reported^{15,16}, concerns arose about access to telecommunications technology, reimbursement, privacy considerations and security of the service¹⁶. Further, broadband access is limited in many areas of the world.

Here we address the perspectives of people living with epilepsy globally on how the pandemic affected them. We also address the experience of healthcare providers with

telehealth, and how we may move forward, particularly in the light of further waves of COVID-19 and other pandemics in the future. Our primary aim was to identify areas where we could provide more resources and guidance for those involved in the care of people living with epilepsy.

2. Methods

At the outset of the pandemic, the International League against Epilepsy (ILAE) brought together a group of epilepsy professionals and people living with epilepsy from around the world to form the Task Force for COVID-19. The Task Force included worldwide representation, as well as members of the International Bureau for Epilepsy (IBE), which represents lay epilepsy organisations including people with epilepsy. A section of the ILAE website was developed with resources for patients, clinicians and researchers (<https://www.ilae.org/patient-care/covid-19-and-epilepsy/>). A portal was enabled for healthcare professionals to report anonymised cases of COVID-19 individuals with new onset seizures, as well as reports of seizure exacerbation in people with epilepsy who experienced symptomatic COVID-19 infection (data collected between 30th April 2020- 30th September 2020). As the information here and below was collected by the ILAE (a U.S.-based organization), was non-identifiable, and was collected for quality improvement to determine additional resources that could be included on the ILAE website, the survey was considered to meet criteria for non-human subject research and thus Institutional Review Board (IRB) approval was waived. We also utilised the NHS Health Research Authority (UK) decision tool (<http://www.hra-decisiontools.org.uk>), the result of which indicated this was not research requiring IRB approval.

In order to address the patient experience through the COVID-19 pandemic, a brief nine-item questionnaire (see Supplemental file 1) was designed by Task Force members for the ILAE, which collected information on 1) whether the respondent was a person with epilepsy (PWE) or the caregiver of a person with epilepsy, 2) country of residence and 3) whether they/child/family member had been diagnosed with COVID-19; 4) whether since the onset of the COVID-19 pandemic the person with epilepsy had a change in seizure frequency and/or 5) difficulty obtaining medication and/or 6) difficulty accessing epilepsy healthcare professionals. The questionnaire also assessed 7) the wellbeing of the person with epilepsy or their caregiver (depending on the respondent) during the last 30 days using the validated 6-item Kessler Psychological Distress Scale (K-6),¹⁷ 8) level of anxiety (as a Likert scale) and 9) any specific information/support needed at this time. This scale was completed by the respondent, either the person with epilepsy or the caregiver referring to themselves. A K-6 cut-off of 13 points was defined as serious mental illness¹⁸ meeting diagnostic criteria for a DSM-IV disorder in the past year whilst experiencing significant impairment. The questionnaire also allowed the respondent to provide comments in textboxes to support their answers. The resulting nine-item questionnaire was available in English, French, Japanese, Spanish, Portuguese, Russian, German, Farsi, Arabic, Italian and Chinese. The questionnaire was evaluated for content validity and clarity by iterative discussions among the Task Force members. Data on patient experience were collected over a 4-month period (7th May 2020-7th September 2020). This questionnaire was hosted on the ILAE website, on the COVID-19 resource webpage and also advertised on the IBE website.

To address telemedicine experience around the world, a 15-item questionnaire was also developed by the Task Force members for the ILAE and formulated into a Google form (Supplemental material 2). Telemedicine was defined as the delivery of medical care with the aid of telecommunications technology, including Internet, cellular, and telephone media.

Teleneurology is the term applied to where this relates to the care in neurology. Items investigated included whether telemedicine was utilised and in what form, associated costs, and internet coverage. The questionnaire was assessed for content validity and clarity by iterative discussions among Task Force members and pilot-tested within the COVID-19 and Telemedicine Task Forces. It was subsequently revised and then disseminated to healthcare professionals through the ILAE newsletter and website and throughout the ILAE's Young Epilepsy Section (YES) membership via SLACK.

Statistical analysis was performed using the R programming environment (Vienna, Austria). Descriptive statistics were used to describe the baseline demographics in our study population and the data for each survey. Between group differences were assessed for significance using chi-squared test. K-6 scores displayed a skewed distribution and Wilcoxon Rank Sum test was applied.

3. Results

3.1. How did COVID-19 affect PWE? Case presentations

The ILAE COVID-19 portal provided the opportunity for health professionals to anonymously report the presentation of new onset seizures and/or exacerbation of seizures in the context of COVID-19 infection. Between May-September 2020, 17 cases were reported (see supplemental material 3); data were limited and therefore no firm conclusions can be drawn although the overall descriptions suggest that most cases had acute symptomatic seizures, or that COVID-19 lowered the threshold for seizure occurrence in individuals with a recognised or unrecognised risk for epilepsy.

3.2. How did the pandemic affect PWE? Responses to the questionnaire

3.2.1 Respondents

A total of 590 respondents (422 PWE, 166 caregivers, 2 did not specify) completed the questionnaire. The number of responses from regions/countries are outlined in Table 1, the majority were from Asia-Oceania (376), followed by Europe (117), and North America (56). Seventeen respondents (2.9%) did not record their country of origin.

Of the 590 respondents (PWE, caregivers, household member), 12.2% (72) stated that they tested positive/were presumably positive or possibly positive (symptoms) for COVID-19.

3.2.2 Seizure impact and access to services

Table 2 summarizes the key findings from the PWE and caregiver questionnaire. Of the 590 respondents, 539 (91%) provided an answer on whether seizure frequency had changed during the COVID-19 period: 22.8% (88/386) PWE and 27.5% (42/153) caregivers reported an increase in seizure frequency. Difficulty obtaining medications during the study period were reported by 19.8% (80/405) of PWE and 26.2% (43/164) of caregivers. A subgroup analysis for countries with more than 10 respondents showed that difficulty in obtained medication ranged from 7% to 48.6% (US: 7.4% (2/27), Ireland: 11.0% (8/73), UK: 11.1% (2/18), Canada: 13.6% (3/22), Australia: 24.0% (66/275), Philippines: 48.6% (17/35).

Difficulty accessing epilepsy healthcare professionals or a support team during the COVID-19 pandemic was reported by 28.1% (113/402) of PWE and 29.9% (49/164) of caregivers.

These difficulties are reported globally. Barriers and facilitators to accessing epilepsy healthcare professionals or support team during the COVID-19 pandemic are listed in Table

3.

3.2.3. Information, communication, and telehealth requirements

A large proportion (58.8%) of PWE (184/315) and caregivers (63/105) felt that they required trustworthy and up-to-date information about epilepsy and COVID-19. About a third (36.4%, 122 PWE, 31 caregivers) indicated that psychological support was paramount, 34.5% (105 PWE, 40 caregivers) wished to receive epilepsy medical advice and support by phone or telehealth visit, 23.6% (69 PWE, 30 caregivers) felt they needed home delivery of medications, 23.3% (68 PWE, 30 caregivers) wished to access to alarms or seizure detection devices, 22.9% (76 PWE, 20 caregivers) conveyed a need for online self-management programs and 12.1% (40 PWE, 11 caregivers) required support for access to food.

3.2.4 Psychological distress

Our study found that 57.1% (173/303) of PWE and 21.5% (23/107) of caregivers had a K-6 score of >13, which is a marker of severe psychological distress.¹⁸ The proportion of people with a K-6 score of >13 was significantly greater among PWEs than among caregivers ($p < 0.01$) (Chi-square).

3.3. How did epilepsy professionals address remote patient care?

3.3.1 Healthcare providers and practice characteristics

A total of 267 healthcare providers completed the telehealth questionnaire. There was representation from 53 countries across all six ILAE regions (Table 4). The mean age of respondents was 50.5 years (range 30-83, SD 10.8) and women represented 55.4% of the sample. The average number of years in clinical practice of respondents was 23.3 years (range 1-56 years, SD 11.1) with the majority working in university hospital settings (n=152;

56.9%) and non-academic community hospitals (n=54; 20.2%), followed by private practice (n=41; 15.4%). Of those who responded, 92.1% (n=246) said they practiced in an urban setting, and very few practiced in rural areas (n=16; 6.0%). The majority of respondents were professors/consultants/specialists (n=245; 91.7%). Areas of expertise were predominantly epilepsy (n=150; 56.2%), general neurology (n=58; 21.7%) and paediatric neurology (n=51; 19.1%).

3.3.2. Teleneurology and healthcare provision

Prior to the COVID-19 pandemic a large proportion of healthcare providers did not use teleneurology (n=166; 62.2%). Since the pandemic, this proportion increased to 87.3% (n=233), with an estimated mean of 40% (IQR 17.5-70) of consultations completed via this method. The most common teleneurology platforms were telephone (n=120; 44.9%), Zoom (n=106; 39.7%), WhatsApp (n=101; 37.8%), text messaging (n=67; 25.1%), Skype (n=38; 14.2%) and FaceTime (n=14; 5.2%). Teleneurology services were most commonly provided by the respondents (n=165; 61.8%) and less frequently by the hospital at which they worked (n=116; 43.4%). Reimbursement was not available for teleneurology in 47.9% (n=128) of practices, with 39.3% (n=105) indicating that there were costs to the respondents when providing care via teleneurology. More than a third of healthcare providers (n=91; 34.1%) also stated that there were costs to their patients when participating in teleneurology, related to hardware/phone/internet charges. In North America (13/18), Latin America (47/78) Eastern Mediterranean (5/7) and Europe (86/112) the majority reported no cost to patients whereas it was a lesser proportion in Africa (4/13) and Asia (7/25).

Most healthcare providers considered teleneurology a useful tool for clinicians (n=246; 92.1%) and for patients (n=244; 91.4%). Furthermore, 74.9% (n=200) of healthcare providers thought that teleneurology was impacting the current care of their patients mostly positively,

but barriers to care were also identified. The advantages of using teleneurology were fast and increased access to care, shorter consultations, prompt feedback, reduced costs, increased follow-ups, while disadvantages included inability to conduct physical examinations and difficulties in reading non-verbal communications.

Two thirds (n=163; 61.0%) of healthcare providers stated that they found no difficulty communicating with their patients during the time of the pandemic. In the third that reported difficulties, the main issues were related to poor connections/no access to internet, elderly patients/low socioeconomic classes not being up to date with technology, and too many calls to be able to answer all. One third (n=85; 31.8%) of providers indicated that internet coverage was good in all areas, 60.7% (n=162) reported that it was good in limited areas/poor in some (n=162; 60.7%), and 5.6% (n=15) poor in most areas.

3.3.3 Teleneurology and patient access

Of all respondents, 54.3% (n=145) and 76.4% (n=204) reported that 100% and >90% of their patients respectively had access to a telephone. A minority (10.5%, n=28) reported that ≤50% of their patients had access to a telephone. On average 74.4% (range 0-100, SD 22.9%) of the respondent's patients had access to the internet. Two thirds (n=159; 59.6%) of healthcare providers noted that hospital policy changes were put into place in light of the pandemic to facilitate access to teleneurology.

4. Discussion: What have we learnt moving forward?

The COVID-19 pandemic has enabled us to learn many lessons. As we gained experience about presentations and treatment of COVID-19, specific risk factors for more severe disease

have become apparent. In a study of primary care records of 17,278,392 adults pseudonymously linked to 10,926 COVID-19-related deaths in England, COVID-19-related mortality was associated with male gender, older age and social deprivation, diabetes, severe asthma, recently diagnosed cancer, organ transplantation and neurological disease, specifically stroke and dementia.¹ A cross-sectional observational study in Spain reported that people with active epilepsy have 2-3-fold increase in the cumulative incidence of COVID-19 compared with people without epilepsy, and that epilepsy is a risk factor for COVID-19 – related mortality among hospitalized patients (OR 5.20 (95%CI 1.4-24.1))¹⁹. However, these conclusions were based on a very small sample of PWE (n=21) admitted to an emergency department, and only 9 of the 21 patients had a COVID-19 diagnosis confirmed by RT-PCR testing. Overall, there is currently insufficient evidence to determine whether epilepsy is amongst the risk factors for severe COVID-19 disease and mortality, although people with epilepsy may of course have associated comorbidities. In theory, neurological manifestations could be expected as the COVID-19 virus exploits the angiotensin converting enzyme 2 (ACE2) receptor to gain entry into cells, and as central nervous system glia and neurons express ACE2 receptors, that makes them potential targets.²⁰ Neurological complications are being recognised, but they are more likely to be related to a hyper-inflammatory syndrome or hyper-coagulopathy²¹ rather than to a direct effect of the SARS-CoV2 virus. Only a limited number of cases with SARS-CoV-2 identified in the cerebrospinal fluid (CSF) have been reported^{22,23}, although a recently published study provided evidence suggesting entry into the central nervous system through the neural-mucosal interface in the olfactory mucosa.²⁴ In initial reports, 0 of 153 patients reported to a surveillance study of COVID-19 and neurological/neuropsychiatric complications,²⁵ 0 of 43 reviewed at a neurological specialist hospital²¹ and 1 of 840 patients in the Spanish ALBACOVID registry presented with seizures in the context of COVID-19,²⁶ with acute cerebrovascular disease emerging as the most

important complication.²⁷ However, many case reports and case series of COVID-19 related seizures (e.g., focal motor, tonic-clonic, convulsive status epilepticus, and nonconvulsive status epilepticus) have been reported in the literature^{19,28}. Our study generated few case reports consistent with these data, with most seizures occurring in those with epilepsy or epilepsy risk factors, but no firm conclusions can be drawn from such reports. Further surveillance with more detailed standardized and prospective reporting and review by epilepsy trained providers should be encouraged.

A further question remains as whether PWE are at risk of exacerbation of seizures in the context of COVID-19 infection. No increase in presentation with status epilepticus was found during the earlier phase of the pandemic.²⁹ Overall available evidence, including the results of our online survey, indicated that a large proportion of PWE experienced difficulties through this time. Many people reported an overall increase in seizures, with difficulties accessing medical care, particularly medications, investigations, information, and self-management. Notable, however, was the degree of psychological distress reported, which may have played a role in causing the reported increase in seizures. Our finding of 57.1% having a K-6 score >13 was far higher than reported in previous studies of PWE (14%)^{30,31} and significantly higher again than K-6 scores previously reported in people without epilepsy (3%).³⁰ While accepting that surveys engage self-reporting from an interested group, these data highlight that the COVID-19 pandemic has added to the mental health burden in an already vulnerable group. In a condition where already there is a higher prevalence of mental health disturbances, many circumstances could exacerbate this^{32,33}, such as unclear access to medical services, as well as home circumstances such as anxiety about others, caregiver stress or financial distress.^{6,34} Increased stress amongst patients may also be related to seeking excess information on the COVID-19 pandemic.³⁵ There are also increasing reports of barriers to obtaining advice from medical services and difficulties in accessing medications

through the pandemic,⁴ all of which can result in an increased risk of seizures, even if not evidenced by increased hospital admissions.^{4,35}

Professionals around the world have tried to ensure continuity of care and enhance contact with their patients through telehealth, with resultant positive experiences.^{9,13,16,36-40} The ILAE survey reached all continents and was completed by relatively experienced practitioners. Two thirds reported no difficulties in utilising a variety of tools and most reported a positive experience. One third reported challenges which included difficulty in connection, as well as user unfamiliarity with the technology (e.g., elderly patients). Many of our respondents worked in urban rather than rural communities, and internet access may not be as reliable in all regions or remote areas.⁴¹ Further, 61% reported that the telehealth facility was provided by themselves rather than their hospital/practice, and reimbursement was not available in 47.9% of cases. It is important to recognise a need for telehealth, acknowledging it is not without limitations. For example, Whatsapp is end to end encrypted, but we acknowledge that it is not compliant, for example, with the Health Insurance Portability and Accountability (HIPAA), and this may be misunderstood in some areas. This said, it is important to ensure continuity of care and consequently the benefits of use of such platforms during the pandemic outweighed the risks. In the future, as the pandemic resolves, it will be important to ensure that such platforms ensure privacy and protection of health information. As the use of telehealth is likely to be a requirement of the future, connectivity must also be seen as a priority in primary care settings around the world, while acknowledging the need for patient privacy and data security. The United Nations have recognised access to the internet as a human right, acknowledging the global and open nature of the Internet as a driving force in accelerating progress towards development in its various forms⁴². Further they have set out a roadmap for digital cooperation aiming that by 2030, every person should have safe and affordable access to the Internet, including meaningful use of digitally enabled services in

line with the Sustainable Development Goals⁴³. The epilepsy community with the support of the ILAE should also advocate for improved telehealth infrastructure with appropriate recognition of such consultations as face to face with regard to reimbursement.

We acknowledge there are limitations to our study. The health professional survey was only circulated in English, would only have been accessible to professionals with internet access, and there was limited participation from some areas e.g., Africa, and none from China.

Reporting of cases of new onset seizures could be by any healthcare professionals, not only physicians with epilepsy expertise. The questionnaire directed to PWE and caregivers was available in many languages and there was a broader geographical representation of respondents. However, respondents would have required access to internet, and needed to have adequate readability level and comprehension. Consequently, accessing and reporting bias are likely to have influenced the results, particularly in low resource regions. We also cannot exclude that patients experiencing distress and other difficulties may have had greater motivation to complete the questionnaire. Our ability to do subgroup analysis with regard to cross regional differences was also limited in view of small numbers. We also did not collect detailed sociodemographics and comorbidities in people with epilepsy as we wanted to minimize the respondent burden and thus are unable to do stratified analyses based on these characteristics.

As we have already seen a second wave of the pandemic, and approach a third and even a fourth wave in some areas, we need to emphasize that epilepsy investigations and elective interventions are possible with appropriate precautions⁴⁴⁻⁴⁸. Acknowledging the burden on healthcare systems, we have a responsibility to continue to provide care to our patients and prevent the expansion of a parallel pandemic of unmet healthcare needs. Although we can rationalise our approach, investigations and consultations cannot be put on hold.

Teleconsultations are here to stay but may not be optimal for all, and careful preparation is

suggested to optimise consultation^{15,49}. PWE need to be aware of how to access an ongoing supply of their regular medication, and when it is necessary to seek urgent care and/or hospital care. Psychological resources and support to both PWE and their caregivers need to be considered in any planning of optimizing healthcare delivery, with a view to enhancing resilience.

Acknowledgements and disclosures on conflict of interest

The data reported in this paper were collected as part of a project undertaken by the International League against Epilepsy (ILAE) and the authors are experts selected by the ILAE. Opinions expressed by the authors, however, do not necessarily represent the policy or position of the ILAE.

JHC has acted as an investigator for studies with GW Pharma, Zogenix, Vitaflo and Marinius. She has been a speaker and on advisory boards for GW Pharma, Zogenix, and Nutricia; all remuneration has been paid to her department. Her research is supported by the National Institute of Health Research (NIHR) Biomedical Research Centre at Great Ormond Street Hospital. She holds an endowed chair at UCL Great Ormond Street Institute of Child Health; she holds grants from NIHR, EPSRC, GOSH Charity, ERUK, and the Waterloo Foundation

CSK is a holder of a Leon Levy Fellowship.

SW received unrestricted educational grants from UCB Pharma, Eisai, Liva Nova and Sunovion.

AI as part of the Department of Epilepsy, Movement Disorders and Physiology as Industry-Academia Collaboration Courses supported by Eisai, Nihon Kohden, Otsuka, and UCB Japan Co., Ltd. AI reports honorariums from Eisai, Otsuka, and UCB Japan.

AAAP, Honoraria from Cobel Daruo, RaymandRad and Tekaje; Royalty: Oxford University Press (Book publication).

EP received speaker's or consultancy fees from Angelini, Arvelle, Biogen, Corlieve, Eisai, GW Pharma, Sanofi, Sun Pharma, UCB Pharma, Xenon Pharma and Zogenix.

ET reports personal fees from EVER Pharma, Epilog, Marinus, Abbott, Argenix, Arvelle, Angelini, Medtronic, Bial – Portela & C^a, S.A., Hikma, Corlieve, Cobel Daruo, NewBridge, GL Pharma, GW Pharmaceuticals, GlaxoSmithKline, Boehringer Ingelheim, LivaNova, Eisai, UCB, Biogen, Genzyme Sanofi, and Actavis; his institution received grants from Biogen, UCB Pharma, Eisai, Red Bull, Merck, Bayer, the European Union, FWF Österreichischer Fond zur Wissenschaftsförderung, Bundesministerium für Wissenschaft und Forschung (FWF), and Jubiläumsfond der Österreichischen Nationalbank outside the submitted work. Royalty: Cambridge University Press and Springer

NJ is the Icahn School of Medicine Bludhorn Professor of International Medicine. She receives grant funding paid to her institution for grants unrelated to this work from NINDS (NIH U24NS107201, NIH IU54NS100064). She also receives an honorarium for her work as an Associate Editor of *Epilepsia*.

NV, GB, PGI, AG, JH, NK, PM, JCPP, ES and DZ have no conflicts to declare

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.

Key points

- 1.** People with epilepsy reported severe psychological distress during the initial period of the COVID-19 pandemic
- 2.** People with epilepsy and their caregivers reported an overall increase in seizures, with difficulties accessing medical care, particularly medications, investigations, information, and self-management.
- 3.** An increase in use of telemedicine was reported by healthcare professionals, with 40% consultations conducted by this method.

References

1. <https://coronavirus.jhu.edu/map.html/> accessed on 21st February 2021
2. Williamson EJ, Walker AJ, Bhaskaran K, Bacon S, Bates C, Morton CE et al. Factors associated with COVID-19 related death using OpenSAFELY Nature 2020;584:430-436
3. Figliozzi S, Masci PG, Ahmadi N, Tondi L, Koutli E, Aimo A et al, Predictors of adverse prognosis in COVID-19: A systematic review and meta-analysis Eur J Clin Invest, 2020 50:e13362
4. Miller WR, Von Gaudecker J, Tanner A, Buelow JM. Epilepsy self-management during a pandemic: Experiences of people with epilepsy. *Epilepsy Behav* 2020; 111: 107238.
5. Asadi-Pooya AA, Farzadaghi M, Bazrafshan M. Impacts of the COVID-19 pandemic on Iranian patients with epilepsy. *Acta Neurol Scand.* 2020;142:392-395
6. Aledo-Serrano Á, Mingorance A, Jiménez-Huete A, Toledano R, García-Morales I, Anciones C et al. Genetic epilepsies and COVID-19 pandemic: Lessons from the caregiver perspective. *Epilepsia* 2020; 61: 1312-1314.,
7. Granata T Bisulli F, Arzimanoglou A, Rocamora R. Did the COVID-19 pandemic silence the needs of people with epilepsy? *Epileptic Disord* 2020;22:439-442
8. López-Bravo A, García-Azorín D, Belvís R, González-Oria C, Latorre G, Santos-Lasaosa S et al Impact of the COVID-19 pandemic on headache management in Spain: an analysis of the current situation and future perspectives *Neurología* . Jul-Aug 2020;35(6):372-380.
9. Wirrell EC, Grinspan ZM, Knupp K, Jiang Y, Hammeed B, Mytinger JR, et al Care Delivery for Children with Epilepsy During the COVID-19 Pandemic: an International Survey of Clinicians. *Journal of Child Neurology.* 2020 Nov;35(13):924-933.
10. Albert DVF, Das RR, Acharya JN, Lee JW, Pollard JR, Punia V et al. The Impact of COVID-19 on Epilepsy Care: A survey of the American Epilepsy Society *Epilepsy Currents* 2020;20:316-324
11. French JA, Brodie MJ, Caraballo R, Devinsky O, Ding D, Jehi L, et al Keeping people with epilepsy safe during the Covid-19 pandemic *Neurology* 2020;94:1032-1037
12. Kuroda N What should we ask patients with epilepsy on telemedicine during the COVID-19 crisis? A checklist for clinicians *Epilepsy & Behavior* 111 (2020) 107184,
13. Rametta SC, Fridinger SE, Gonzalez AK, Xian J, Galer PD, Kaufman M, et al Analyzing 2,589 child neurology telehealth encounters necessitated by the COVID-19 pandemic. *Neurology* . 2020 Sep 1;95(9):e1257-e1266.
14. Kuchenbuch M, D'Onofrio G, Wirrell EC, Jiang Y, Dupont S, Grinspan ZM, et al An accelerated shift in the use of remote systems in epilepsy due to the COVID-19 pandemic. *Epilepsy Behav.* 2020 Nov;112:107376.

15. Casares M, Wombles C, Skinner HJ, Westerveld M, Gireesh ED. Telehealth perceptions in patients with epilepsy and providers during the COVID-19 pandemic. *Epilepsy Behav.* 2020 Nov;112:107394.,
16. Subotic A, Pricop DF, Josephson CB, Patten SB, Smith EE, Roach P et al. Examining the impacts of the COVID-19 pandemic on the well-being and virtual care of patients with epilepsy *Epilepsy & Behavior* 2020;113:107599.
17. Kessler R.C., Berglund P.A., Zhao S., Leaf P.J., Kouzis A.C., Bruce M.L., et al The 12-month prevalence and correlates of serious mental illness In *Mental Health, United States, 1996*, Manderscheid R.W., Sonnenschein M.A. (eds) pp. 59–70, Washington, DC, US Government Printing Office
18. Prochaska JJ, , Sung HY, Max W, Shi Y, Ong M. Validity study of the K6 scale as a measure of moderate mental distress based on mental health treatment need and utilization *Int J Methods Psychiatr Res* 2012;21:88-97.
19. Cabezudo-Garcia P, Ciano Petersen NL, Mena-Vazquez N Pons-Pons G, Castro-Sánchez MV, Serrano-Castro PJ. Incidence and case fatality rate of COVID-19 in patients with active epilepsy *Neurology* 2020;95:e1417-e1425
20. Baig AM, Khaleeq A, Ali U, Syeda H. Evidence of the COVID-19 Virus Targeting the CNS: Tissue Distribution, Host–Virus Interaction, and Proposed Neurotropic Mechanisms *ACS Chem. Neuroscience* 2020;11:995-998.
21. Paterson RW, Brown RL, Benjamin L Nortley R, Wiethoff S, Bharucha T, et al The emerging spectrum of COVID-19 neurology: clinical, radiological and laboratory findings *Brain* 2020;143:3104-3120
22. Moriguchi T, Harii N, Goto J, Harada D, Sugawara H, Takamino J, et al. A first case of meningitis/encephalitis associated with SARS-Coronavirus-2. *Int J Infect Dis* 2020; 94: 55-58.
23. Helms J, Kremer S, Merdji H, Schenck M, Severac F, Clere-Jehl R, et al. Delirium and encephalopathy in severe COVID-19: a cohort analysis of ICU patients. *Crit Care* 2020; 24: 491.
24. Meinhardt J, Radke J, Dittmayer C, Franz J, Thomas C, Mothes R et al. Olfactory transmucosal SARS-CoV-2 invasion as a port of central nervous system entry in individuals with COVID-19. *Nature Neuroscience* 2020; <https://doi.org/10.1038/s41593-020-00758-5>
25. Varatharaj A, Thomas N, Ellul TN, Davies NWS, Pollak TA, Tenorio EL, et al Neurological and neuropsychiatric complications of COVID-19 in 153 patients: a UK-wide surveillance study *Lancet Psychiatry* 2020;7:875-882
26. Romero-Sanchez CM, Diaz-Matoto I, Fernandez-Diaz E, Sánchez-Larsen Á, Layos-Romero A, García-García J et al Neurologic manifestations in hospitalised patients with COVID-19; The ALBACOVID registry *Neurology* 2020;95:e1060-e1070
27. Mao L, Jin H, Wang M, Hu Y, Chen S, He Q et al. Neurologic manifestations of hospitalized patients with coronavirus disease 2019 in Wuhan, China. *JAMA Neurol* 2020;77:683-690

28. Asadi-Pooya AA, Simani L, Shahisavandi M, Barzegar Z. COVID-19, de novo seizures, and epilepsy: a systematic review. *Neurol Sci* 2020: 1-17
29. Leitinger M, Popper KN, Mauritz M, Rossini F, Zimmermann G, Rohrer A et al. Status epilepticus admissions during the COVID-19 pandemic in Salzburg- A population based study. *Epilepsia* 2020;61:e198-e203
30. Kobau R, Sapkota S, Zack MM. Serious psychological distress among adults with active epilepsy in all racial/ethnic groups and among adults with inactive epilepsy in non-Hispanic whites in significantly higher than among adults without epilepsy – US National Health Interview Survey, 2010, 2013, 2015 and 2017. *Epilepsy & Behavior* 2019;95:192-194
31. Moore JL, Elliott JO, Klatte ET, Charyton C. Serious psychological distress among persons with epilepsy based on the 2005 California Health Interview Survey. *Epilepsia* 2009;50:1077-1084
32. Assenza G, Lanzone J, Brigo F, Coppola A, Di Gennaro G, Di Lazzaro V, et al. Epilepsy Care in the Time of COVID-19 Pandemic in Italy: Risk Factors for Seizure Worsening. *Front Neurol* 2020; 11: 737.
33. Hao X, Zhou D, Li Z, Zeng G, Hao N, Li E et al Severe psychological distress among patients with epilepsy during the COVID-19 outbreak in southwest China *Epilepsia*. 2020 Jun;61(6):1166-1173
34. Kuroda N Mental health considerations for patients with epilepsy during COVID-19 crisis *Epilepsy & Behaviour* 220;111:107198
35. Huang S, Wu C, Jia Y, Li G, Zhu Z, Lu K et al. COVID-19 outbreak: The impact of stress in patients with epilepsy *Epilepsia* 2020;61:1884-1893
36. Conde-Blanco E, Centeno M, Tio E, Muriana D, García-Peñas JJ, Serrano P, et al. Emergency implementation of telemedicine for epilepsy in Spain: Results of a survey during SARS-CoV-2 pandemic. *Epilepsy Behav* 202; 111: 107211
37. Kumar Panda P, Dawman L, Panda P, Kumar Sharawat I Feasibility and effectiveness of teleconsultation in children with epilepsy amidst the COVID pandemic in a resource limited country *Seizure* 2020;81:29-35.
38. Punia V, Nasr G, Zagorski V, Lawrence G, Fesler J, Nair D, et al. Evidence of a Rapid Shift in Outpatient Practice During the COVID-19 Pandemic Using Telemedicine. *Telemed J E Health*. 2020;26:1301-1303
39. Wirrell EC, Grinspan ZM, Knupp KG, Jiang Y, Hammeed B, Mytinger JR et al Care delivery for children with epilepsy during the COVID19 pandemic; an international survey of clinicians. *J Child Neurol* 2020;35:924-933
40. Power K, McCrea Z, White M, Breen A, Dunleavy B, O'Donoghue S, et al. The development of an epilepsy electronic patient portal: Facilitating both patient empowerment and remote clinician-patient interaction in a post-COVID-19 world. *Epilepsia* 2020;61:1894-1905
41. Alliance for affordable internet. Rural broadband policy framework: connecting the unconnected <https://a4ai.org/meaningful-connectivity/>

42. https://www.article19.org/data/files/Internet_Statement_Adopted.pdf accessed 21st February 2021
43. <https://www.un.org/en/content/digital-cooperation-roadmap/> accessed 21st February 2021
44. Grinspan ZM, Mytinger JR, Baumer FM, Ciliberto MA, Cohen BH, Dlugos DJ et al Management of Infantile Spasms During the COVID-19 Pandemic. *J Child Neurol.* 2020 Oct;35(12):828-834.
45. Gélisse P, Rossetti AO, Genton P, Crespel A, Kaplan PW How to carry out and interpret EEG recordings in COVID-19 patients in ICU? *Clin Neurophysiol.* 2020 Aug;131(8):2023-2031.
46. <https://www.acns.org/practice/covid-19-resources>
47. Beniczky S, Husain A, Ikeda A, Alabri H, Helen Cross J, Wilmshurst J, et al. Importance of access to epilepsy monitoring units during the COVID-19 pandemic: Consensus statement of the International League against epilepsy and the International Federation of Clinical Neurophysiology. *Clin Neurophysiol.* 2021 Jul 15:S1388-2457(21)00567-8. doi: 10.1016/j.clinph.2021.05.001. Epub ahead of print. PMID: 34275732; PMCID: PMC8294085.
48. Beniczky S, Husain A, Ikeda A, Alabri H, Cross JH, Wilmshurst J, et al. Importance of access to epilepsy monitoring units during the COVID-19 pandemic: consensus statement of the International League Against Epilepsy and the International Federation of Clinical Neurophysiology. *Epileptic Disord.* 2021 Jul 15. doi: 10.1684/epd.2021.1292. Epub ahead of print. PMID: 34266813.
49. <https://www.ilae.org/files/dmfile/Telemedicine-in-PWE-2020-0925.pdf>

Table 1: Countries of response from PWE and caregivers

	PWE	Caregivers	Total
Asia Oceania			
Australia	197	77	274
China	35	18	53
The Philippines	21	14	35
Japan	7	4	11
Other: (Bangladesh, India, New Zealand)	1	2	3
Europe			
Ireland	59	15	74
UK	15	4	19
Malta	4	6	10
Other (Albania, Belgium, France Sweden, Switzerland, Portugal, Russia, Serbia, Spain)	9	5	14
North America	29	5	34
USA	20	2	22
Canada			
Latin America (Chile, Brazil, Columbia, Mexico, Peru)	6	2	8
Africa (South Africa, Burundi, Kenya, Nigeria, Uganda)	5	4	9
Eastern Mediterranean (Egypt, Jordan, Sudan)	2	3	5
No record of country of origin	12	5	17
No record whether PWE or caregivers			2
Total	422	166	590

Table 2: Questionnaire responses from patients with epilepsy and caregivers

	Patients	Caregivers
Reported seizure change	88/386	42/153
Difficulty obtaining medication	80/405	43/164
Difficulty accessing healthcare	113/402	49/164
Require trustworthy information	184/315	63/105
Desired psychological support	122/315	31/105
K-6 score >13	173/303	23/107

F = female; M = male; K-6 = Kessler Psychological Distress Scale

Table 3 - Barriers and facilitators accessing epilepsy healthcare professionals or support team during the COVID-19 period

Barriers	
Delayed investigations/therapeutics (e.g., blood tests, EEG, MRI, epilepsy surgery),	<i>“I cannot take my EEG test”, “Hard to get blood tests done”, “Waiting for left temporal lobectomy and also had to have my appointment via phone not regular appointment and testing”</i>
Cancellation of appointments	<i>“My epilepsy nurse is unavailable as she is on frontline”, “More difficulty getting appointments”, “Neurologist hasn’t been available or responding to referrals”, “Unable to see my Neurologist due to him much busier than usual”</i>
Limited access to healthcare providers due to provider limited availability	<i>“Not sure where and when to contact them”, “I never really got a support team and now it’s just impossible”, “I wish I had support”, “Took several weeks to obtain medication”</i>
Fear of going to healthcare facility	<i>“Afraid to meet my neurologist in person because of traveling during COVID”, “Trying to avoid hospitals”</i>
Dissatisfaction with telehealth	<i>“No face-to-face consultation”, “Telephone specialist consults not as successful”</i>
Limited access to healthcare providers due to travel restrictions	<i>“Was unable to see neurologists due to State lines being closed”</i>
Facilitators	
Availability of telehealth	<i>“Consultations via phone was made possible by my attending Neurologist”</i>

Table 4: Countries from which response received to telehealth questionnaire

Region	No of responses N=267	Countries
Europe	123	Albania, Belgium, Croatia, Estonia, France, Georgia, Germany, Hungary, Ireland, Latvia, Lithuania, Luxembourg, Netherland, Macedonia, Poland, Portugal, Romania, Switzerland, Turkey, Ukraine
Latin America	78	Argentina, Bolivia, Brazil, Chile, Colombia, Cuba, Ecuador, El Salvador, Honduras, Mexico, Peru, Uruguay
Asia Oceania	25	India, Indonesia, Japan, Malaysia, Myanmar, Philippines, New Zealand
North America	19	Canada, USA
Africa	14	Burkina Faso, Burundi, Nigeria, Cote D'Ivoire, Ghana, Kenya
Eastern Mediterranean	7	Bahrain, Egypt, Iran, Morocco, Tunisia, Qatar
Not reported	1	