

## SPECIAL REPORT

## Epilepsy care during the COVID-19 pandemic

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**Abstract**

The coronavirus disease 2019 (COVID-19) pandemic has affected the 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 health care professionals, how the pandemic has affected the well-being, care, and services for PWE. 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 health care providers could report cases of new-onset seizures or an exacerbation of seizures in the context of COVID-19. Finally, a separate questionnaire aimed at exploring the utilization of telehealth by health care professionals since the pandemic began was available on the ILAE website and also disseminated to its members. Seventeen 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 health care 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 among PWE than caregivers ( $p < 0.01$ ). An increase in telemedicine use during the COVID-19 pandemic was reported by health care professionals, with 40% of consultations conducted by this method. Although 74.9% of health care 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 health care needs.

**KEYWORDS**

COVID-19, people with epilepsy, psychological distress, telemedicine

**1 | INTRODUCTION**

The coronavirus disease 2019 (COVID-19) pandemic has affected everyone around the world, not least through pressure on health care systems and delivery of care. The initial wave and consequent lockdowns led to the cancellation of routine investigations and elective interventions, and many health care providers had to move to alternative models of care delivery.

First reported in China, COVID-19 is caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). SARS-CoV-2 infection is associated with a respiratory illness of varying severity, from asymptomatic to respiratory distress syndrome to multiorgan failure with a hypercoagulable and/or hyperinflammatory syndrome associated with high mortality. Tens of millions of cases of COVID-19 have been confirmed globally, with millions

**Key points**

1. People with epilepsy reported severe psychological distress during the initial period of the coronavirus disease 2019 (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 the use of telemedicine was reported by health care professionals, with 40% of consultations conducted by this method.

of resultant deaths worldwide.<sup>1</sup> 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 (eg, diabetes, obesity, cardiovascular disease, kidney disease, cancer, chronic respiratory disease).<sup>2,3</sup> Furthermore, in the midst of the pressure on health care systems, there is evidence that health care 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.<sup>4-8</sup>

As the pandemic hit and services shut down, health care professionals attempted to address the needs of people with epilepsy,<sup>9-14</sup> with a specific focus on telehealth and remote working. Although in some areas positive outcomes were reported,<sup>15,16</sup> concerns arose about access to telecommunications technology, reimbursement, privacy considerations, and security of the service.<sup>16</sup> Furthermore, broadband access is limited in many areas of the world.

Here we address the perspectives on how the pandemic affected people living with epilepsy globally. We also address the experience of health care 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 organizations 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 health care professionals to report anonymized 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 April 30 and September 30, 2020). Because the information here and below collected by the ILAE (a U.S.-based organization), was nonidentifiable, 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 nonhuman subject research and thus institutional review board (IRB)

approval was waived. We also utilized the NHS Health Research Authority (UK) decision tool (<http://www.hra-decisiontools.org.uk>), the results of which indicated this was not research requiring IRB approval.

To address the patient experience through the COVID-19 pandemic, a brief nine-item questionnaire (see Supporting Information 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) the 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 health care professionals. The questionnaire also assessed (7) the well-being 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),<sup>17</sup> (8) the 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 illness<sup>18</sup> meeting diagnostic criteria for a Diagnostic Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) disorder in the past year while 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 (from May 7 to September 7, 2020). This questionnaire was hosted on the ILAE website on the COVID-19 resource webpage and was 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 (Supporting Information 2). Telemedicine was defined as the delivery of medical care with the aid of telecommunications technology, including the Internet, cellular, and telephone media. Teleneurology is the term applied to where this relates to care in neurology. Items investigated included whether telemedicine was utilized and in what form, the 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 health care 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 the chi-square test. K-6 scores displayed a skewed distribution and the 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 care professionals to anonymously report the presentation of new-onset seizures and/or exacerbation of seizures in the context of COVID-19 infection. Between May and September 2020, a total of 17 cases were reported (see Supporting Information 3). Data were limited, and therefore no firm conclusions could 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 recognized or unrecognized 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 members), 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%)

**TABLE 1** Countries of response from PWE and caregivers

	PWE	Caregivers	Total
<b>Asia Oceania</b>			
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
<b>Europe</b>			
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
<b>North America</b>			
United States	29	5	34
Canada	20	2	22
<b>Latin America</b> (Chile, Brazil, Columbia, Mexico, Peru)			
	6	2	8
<b>Africa</b> (South Africa, Burundi, Kenya, Nigeria, Uganda)			
	5	4	9
<b>Eastern Mediterranean</b> (Egypt, Jordan, Sudan)			
	2	3	5
No record of country of origin	12	5	17
No record whether PWE or caregivers			2
<b>Total</b>	<b>422</b>	<b>166</b>	<b>590</b>

provided an answer about 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 was 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 obtaining 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], and the Philippines: 48.6% [17/35]).

Difficulty accessing epilepsy health care 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 health care 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.<sup>18</sup> 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 | Health care providers and practice characteristics

A total of 267 health care 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, standard deviation [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 nonacademic 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 pediatric neurology ( $n=51$ ; 19.1%).

### 3.3.2 | Teleneurology and health care provision

Prior to the COVID-19 pandemic, a large proportion of health care 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% (interquartile range [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 health care 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 health care 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 health care 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, and increased follow-ups, whereas disadvantages included an inability to conduct physical



examinations and difficulties in reading nonverbal communications.

Two thirds (n=163; 61.0%) of health care 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 the 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.

**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

Abbreviations: F, female; K-6, Kessler Psychological Distress Scale; M, male.

**TABLE 3** Barriers and facilitators accessing epilepsy health care professionals or support team during the COVID-19 period

Barriers	
Delayed investigations/therapeutics (eg, 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 health care 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 health care 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 health care 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>

### 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 health care 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, social deprivation, diabetes, severe asthma, recently diagnosed cancer, organ transplantation, and neurological disease (specifically stroke and dementia).<sup>1</sup> A cross-sectional observational study in Spain reported that

Region	No. of responses N=267	Countries
Europe	123	Albania, Belgium, Croatia, Estonia, France, Georgia, Germany, Hungary, Ireland, Latvia, Lithuania, Luxembourg, Netherlands, 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, United States
Africa	14	Burkina Faso, Burundi, Nigeria, Cote D'Ivoire, Ghana, Kenya
Eastern Mediterranean	7	Bahrain, Egypt, Iran, Morocco, Tunisia, Qatar
Not reported	1	

**TABLE 4** Countries from which response received to telehealth questionnaire

people with active epilepsy have a 2- to 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 (odds ratio [OR] 5.20; 95% confidence interval [CI] 1.4–24.1).<sup>19</sup> 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 reverse transcription-polymerase chain reaction testing. Overall, there is currently insufficient evidence to determine whether epilepsy is among the risk factors for severe COVID-19 disease and mortality, although people with epilepsy may have associated comorbidities. In theory, neurological manifestations could be expected because the SARS-CoV-2 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.<sup>20</sup> Neurological complications are being recognized, but they are more likely to be related to a hyperinflammatory syndrome or hypercoagulopathy<sup>21</sup> rather than to a direct effect of SARS-CoV-2. Only a limited number of cases with SARS-CoV-2 identified in the cerebrospinal fluid (CSF) have been reported,<sup>22,23</sup> although a recently published study provided evidence suggesting entry into the central nervous system through the neural-mucosal interface in the olfactory mucosa.<sup>24</sup> In initial reports, 0 of 153 patients reported to a surveillance study of COVID-19 and neurological/neuropsychiatric complications,<sup>25</sup> 0 of 43 reviewed at a neurological specialist hospital,<sup>21</sup> and 1 of 840 patients in the Spanish

ALBACOVID registry presented with seizures in the context of COVID-19,<sup>26</sup> with acute cerebrovascular disease emerging as the most important complication.<sup>27</sup> However, many case reports and case series of COVID-19-related seizures (eg, focal motor, tonic-clonic, convulsive status epilepticus, and nonconvulsive status epilepticus) have been reported in the literature.<sup>19,28</sup> Our study generated few case reports consistent with these data, with most seizures occurring in patients 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 to 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.<sup>29</sup> 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 that reported in previous studies of PWE (14%)<sup>30,31</sup> and significantly higher again than K-6 scores reported previously in people without epilepsy (3%).<sup>30</sup> Although 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 there is already a higher prevalence of mental health disturbances, many circumstances could exacerbate this,<sup>32,33</sup> such as unclear access to medical services, as well as home circumstances such as anxiety about others, caregiver stress, or financial distress.<sup>6,34</sup> Increased stress among patients may also be related to seeking excess information about the COVID-19 pandemic.<sup>35</sup> There are also increasing reports of barriers to obtaining advice from medical services and difficulties in accessing medications through the pandemic,<sup>4</sup> all of which can result in an increased risk of seizures, even if not evidenced by increased hospital admissions.<sup>4,35</sup>

Professionals around the world have tried to ensure continuity of care and enhance contact with their patients through telehealth, with resultant positive experiences.<sup>9,13,16,36–40</sup> The ILAE survey reached all continents and was completed by relatively experienced practitioners. Two thirds reported no difficulties in utilizing 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 (eg, 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.<sup>41</sup> Furthermore, 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 recognize 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. That 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. Because the use of telehealth is likely to be a requirement in 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 has recognized access to the Internet as a human right, acknowledging the global and open nature of the Internet as a driving force in accelerating progress toward development in its various forms.<sup>42</sup> Furthermore, 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 Goals.<sup>43</sup> 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 that 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, for example, Africa, and none from China. Reporting of cases of new-onset seizures could be by any health care professional, 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 an 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 precautions.<sup>44–48</sup> Acknowledging the burden on health care systems, we have a responsibility to continue to provide care to our patients and prevent the expansion of a parallel pandemic of unmet health care needs. Although we can rationalize 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 optimize consultation.<sup>15,49</sup> 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 health care delivery, with a view to enhancing resilience.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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