

Did the COVID-19 pandemic silence the needs of people with epilepsy?

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ABSTRACT – Aims. The COVID-19 pandemic shook European healthcare systems, with unavoidable gaps in the management of patients with chronic diseases. We describe the impact of the pandemic on epilepsy care in three tertiary epilepsy centres from Spain and Italy, the most affected European countries.

Methods. The three epilepsy centres, members of the European EpiCARE network, manage more than 5,700 people with epilepsy. In Bologna and Barcelona, the hospitals housing the epilepsy centres were fully converted into COVID-19 units. We describe the reorganization of the clinics and report on the frequency of SARS-CoV-2 in people with epilepsy as well as the frequency of seizures in patients admitted to the COVID units. Finally, we elaborate on critical issues regarding the second phase of the pandemic.

Results. The activities related to epilepsy care were reduced to less than 10% and were deprioritized. Discharges were expedited and elective epilepsy surgeries, including vagal nerve stimulator implantations, cancelled. Hospitalizations and EEG examinations were limited to emergencies. The outpatient visits for new patients were postponed, and follow-up visits mostly managed by telehealth. Antiseizure medication weaning plans and changes in vagal nerve stimulator settings were halted. Among the 5,700 people with epilepsy managed in our centres, only 14 tested positive for SARS-CoV-2, without obvious impact on their epilepsy. None of the 2,122 patients admitted to COVID units experienced seizures among the early symptoms.

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Conclusion. Epilepsy care was negatively impacted by the pandemic, irrespective of COVID-19 epidemiology or conversion of the hospital into a COVID-19 centre. The pandemic did not silence the needs of people with epilepsy, and this must be considered in the planning of the second phase.

Key words: COVID-19, epilepsy, chronic disease, pandemic, SARS-CoV-2

Epilepsy affects around 50 million people worldwide, and six million in Europe. The coronavirus-disease-2019 (COVID-19) pandemic spread to Europe between the end of February and mid-March 2020, with the highest number of cases and deaths recorded in Spain and northern Italy. On May 8th, the World Health Organization reported 215,858 cases with 29,958 associated deaths in Italy (65% of which were reported in Lombardy and Emilia Romagna), and 221,447 cases with 26,070 associated deaths in Spain (WHO, COVID-19 situation report, 2020). Quarantine measures to limit contagion were put in place and progressively tightened until the lockdown which, in Italy, were relaxed on May 4th.

The pandemic shook the healthcare systems of these countries, with unavoidable gaps in the care of patients with chronic diseases, including epilepsy.

In this report, three epileptologists from Italy and Spain summarize the impact of COVID-19 on the organization of their hospitals and the consequences on the care of people with epilepsy (PWE). A preliminary report of these experiences was given during the Webinar organized by EpiCARE, the European Reference Network (ERN) for rare and complex epilepsies, on April 7th, 2020.

Methods

Each author retraced the changes which were required in their hospitals to cope with the COVID-19 emergency, and critically reviewed the impact of these changes on PWE. The authors shared their experiences and exchanged their views at the webinar, and, further, through emails and online meetings. The three experiences refer to a paediatric epilepsy unit (PEU) in a non-COVID hospital (Neurologic Institute, Milano, Lombardy), and to two epilepsy centres, mainly devoted to adult patients, in institutes converted into COVID hospitals (Neurologic Institute, Bologna, Emilia Romagna, and Hospital del Mar, Barcelona). The three epilepsy centres are third-level centres and are members of the ERN EpiCARE.

The three epilepsy centres have in- and outpatient clinics dedicated to people with epilepsy, EEG units, an epilepsy monitoring unit (EMU) for long-term video-EEG monitoring (LT-V-EEG) and programs for epilepsy surgery. The Milan centre takes care of around

4,000 PWE of whom 40% are from outside Lombardy; the PEU manages around 1,300 children a year. The Bologna Centre manages 2,131 PWE/year, from within and outside the region, 20% of whom suffer from drug-refractory seizures. The Barcelona centre is a national reference unit and manages 2,300 PWE; its EMU is equipped with beds for LT-V-EEG and stereo-electroencephalography (sEEG) pre-surgical studies.

Results

At the end of February, within days after the outbreak, all activities were reduced to less than 10% and deprioritized in all the three centres. In epilepsy clinics, discharges were expedited, including patients who did not complete LT-V-EEG monitoring. Elective epilepsy surgeries and vagal nerve stimulator (VNS) implantations were cancelled. Hospitalizations and EEG examinations were limited to emergencies. Management of *status epilepticus* (SE) was particularly challenging in centres where intensive care unit (ICU) beds were committed to the care of COVID-19 patients.

The outpatient clinics were reorganized to balance safety measures for patients and personnel, with continuity of care. In all three centres, rescheduling of appointments was triaged by telephone calls. New patients' visits were mostly postponed and follow-up visits managed by tele-health. Antiseizure medication (ASM) weaning plans and changes to VNS settings were halted.

In the EEG labs, hyperventilation was avoided to protect staff, in line with the recommendations of the American Clinical Neurophysiology Society (ACNS, 2020); a specific protocol was applied to COVID-19 patients (*box 1*). For seizure detection, home-video was encouraged, especially for patients experiencing new-onset epilepsy, changes in semiology or psychogenic seizures (Tatum *et al.*, 2020). All patients were provided with a dedicated telephone number for direct consultation with a physician. The very strict lockdown rules made it virtually impossible for patients to receive a paper prescription; this was managed by allowing electronic prescription of drugs at pharmacies, extension of therapeutic plans for special treatments, and driving license renewals. Many Italian patients were unable to obtain testing for plasma ASM levels because several hospitals and labs did not consider this to be essential.

Box 1. EEG protocol for COVID+ / patients under investigation

Inquire about COVID/PUI status prior to the procedure. For PUI - Ask the clinical team if the procedure can be postponed until test results are available. The treatment team is responsible for determining the appropriateness of diagnostic tests. For any decision-making regarding a procedure or test, the risks associated with potential healthcare worker exposure should be balanced against medical necessity.

- EEG at bedside for inpatients
- Two technicians: one interacting with patient, the other in charge of the recording
- Rapid-application EEG with disposable, single-use caps/ templates particularly if technical staffing is limited
- Clear plastic bags to cover EEG equipment
- Keep the machine outside the patient's room (via long wiring). This minimizes equipment contamination and the amount of time the EEG technician needs to stay in the room
- Hyperventilation should not be performed
- Personnel protection equipment (PPE)
 - Technician:
 - PAPR or fit-tested N95. If N95/PAPR respirator is not available, a surgical face mask is considered an appropriate alternative, especially for the technician in charge of the recording
 - face shield or goggles
 - non-sterile gloves
 - COVID+/PUI
 - non-sterile gloves
 - surgical mask

PPE may be re-used but in accordance with institutional protocols. The CDC recommends conservation of PPE given short supply. Currently, N95 is used for 8 hours, and surgical masks for 2-4 hours.

- Cleaning:
 - Respiratory protection should always be put on (donned) first and should be the last to be removed (doff)
 - Always remove PPE in the least contaminated way possible
 - Use antiseptic wipes (alcohol 70%) to clean all surfaces of the NDT equipment that has entered any COVID+/PUI patient room
 - See U Maryland equipment cleaning protocol
- Policies and procedures are rapidly evolving and vary considerably between institutions and units, therefore, current national and institutional updates should be followed.

PUI: patient under investigation; PAPR: powered air purifying respirators; NDT: non-destructive testing specialists; CDC: centre for disease control and prevention.

Delivery of epilepsy care was also influenced by staff reductions (up to 70% less staff), due to illness or self-quarantine, and to the relocation of personnel to COVID-19 duty. At the very beginning of the epidemic, staff protection protocols changed weekly, based on regional and national policies. The lack of safety procedures and personal protective equipment (PPE) most likely contributed to virus spread among healthcare workers. PPE, which varies according to the risk associated with different procedures, is now available for healthcare workers although there are concerns for the second phase, when the need for PPE will dramatically increase. Currently, the safety procedures have been refined and include a telephone interview regarding COVID-19 symptoms, including hyposmia and hypogeusia (Giacomelli *et al.*, 2020), as well as temperature screening and mandatory wearing of surgical masks at the hospital entrance. Inflammatory screens and nasopharyngeal swab testing are required for inpatients admission. Only one accompanying person is allowed with each in- or outpatient.

When the COVID-19 crisis broke out, a frequent query was whether a possible increased risk of SARS-CoV-2 infection would occur in PWE, with potential seizure worsening. A further issue was whether new-onset seizures might be a symptom of COVID-19.

Overall, in our experience, seizures were never the presenting symptom in the 2,122 patients admitted to the COVID units in Bologna and Barcelona over the two-month period, and only rarely appeared in the course of the disease. Among the 5,700 PWE (4,400 adults and 1,300 children) managed in our epilepsy centres, only 14 tested positive for SARS-CoV-2, without obvious impact on their epilepsy. More generally, our patients did not report significant changes in seizure frequency during the COVID emergency, and, surprisingly, the number of patients' calls significantly decreased. The lifestyle modification imposed by the lockdown, the improved compliance with treatment and sleep regularity, leading to better seizure control, may explain the reduced need for consultation. In other cases, patients' reluctance to get in touch with doctors, however, might also have been due to a fear of the hospital as an amplifier of infection. This reluctance carries the risk of underestimating any alarming symptoms; the delayed access to the emergency department may potentially lead to an increased number of super-refractory SE, with a mortality rate which might be increased by the shortage of ICU beds.

Another critical issue in epilepsy care during the COVID-19 outbreak was handling comorbidities, including mental and motor disabilities. The preliminary results of a survey carried out in Milan on 409 families with children with epilepsy showed that families were particularly distressed by the worsening or occurrence of behavioural disorders.

The interruption of routine and rules imposed by the lockdown caused loss of acquired skills and autonomy, regressive behaviour, severe hyperactivity, and explosions of anger in patients with intellectual disabilities and psychiatric comorbidity, with ensuing increased family burden. The psychological support we provided by telephone was appreciated but not sufficient to address family needs.

Discussion

Our experiences indicate that, in the past two months, epilepsy care was negatively impacted by the pandemic, irrespective of COVID-19 epidemiology or conversion of hospitals into exclusive COVID-19 centres. The pandemic did not silence the needs of PWE, and this must be considered for future planning strategies to cope with the imminent second phase. In the “new normal” scenario (Berwick, 2020), there will be a profound change in the organization of hospitals, with regard to social distancing of personnel and patients, PPE, and COVID-related triage. The admission capacity will decrease for both out- and inpatients. The epilepsy centres, therefore, will have to consider appropriate procedures to triage patients who need hospitalization, in-person visits, and diagnostic as well as pre-surgical and surgical procedures. Prioritization will require a balance between healthcare resources and ethics, to ensure the best standard of care to all PWE. Guidelines have to be drawn to prioritize interventions for candidates of epilepsy surgery, in order to favour those with the highest chances of benefit (e.g. patients with life-threatening seizures, children, and women of childbearing age).

To limit the transfer of patients, the epilepsy centres will have to interact with peripheral hospitals and general practitioners, and create networks to ensure care to PWE. Educational and teaching activities will aid non-specialists in coping with epilepsy emergencies (new-onset seizures, increased seizure frequency, change in semiology, SE, onset of neurologic deficits, severe treatment-related side effects, and behavioural disorders). Teleconsulting will be implemented for patients who do not require physical or laboratory examination. This, however, cannot replace in-person consultation for PWE with special needs (e.g. children with mental and psychiatric comorbidities, pregnant women). Tele-health is governed by administrative and economic rules: will the insurance companies and public health systems reimburse the cost of telemedicine services, and how will this be done (Bloem *et al.*, 2020)?

The need for social distancing will influence the everyday *modus operandi* of healthcare workers. Multidisciplinary care meetings, educational activities, and

scientific conferences will be carried out on online platforms; students and residents will rotate within departments, as recommended by the Accreditation Council for Graduate Medical Education (ACGME, 2020). Remote working will have to be favoured for activities not strictly related to the in-person management of patients.

We have reported our experience in managing PWE during the COVID-19 outbreak to point out the difficulties in balancing the needs of safety measures related to infection against adequate care to patients with chronic diseases. Filling this gap will be the challenge for the next months. Recommendations have been developed by the scientific community (French *et al.*, 2020); nevertheless, additional efforts are desperately needed to prepare in providing optimal care to all patients with chronic diseases during health emergencies. □

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