

Editorial

Epilepsy Care in Pandemic Times: When the Going Gets Tough, the Tough Gets Going

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The issue that has come to define the present doctor–patient relationships at most levels of chronic health care beside the scale of public health issues that has emanated from it, is the coronavirus disease of 2019 (COVID-19) pandemic. While this has the potential to effect everyone worldwide, its impact on persons with chronic health conditions is being increasingly recognized in terms of challenges in consistency of not only health care delivery but also managing emergent concerns. Persons with epilepsy as well as their families/caregivers and the health care providers face further consequences of the pandemic. Their risk of contracting the virus compounds with emergency room (ER) visits or hospital admissions. COVID-19 is thus proving to be the scourge of persons with chronic health care conditions.

The numbers of cases of COVID-19 are being increasingly reported from many resource-limited countries, with India and the subcontinent as a whole emerging as a hotspot of infection after making a reasonable start in terms of initial control of the infectivity rate of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). “Unlocking” seems to have exponentially increased the rate of transmission of the virus, with the lockdown expected to have a preemptive role in preventing a burden on intensive and clinic-based or indoor health care service providers. Our current health care systems are likely to encounter tremendous stress with the massive rise in the number of infected cases despite the attempts to improve the available health care infrastructure by the Centre and States. Telemedicine services have emerged as an important tool, which, however, remains inaccessible to patients of the lower socioeconomic strata. Medication online delivery systems are still to be in regular use in towns and villages with logistic challenges in prescription

acquisition and purchase to compound the stigma already attached to epilepsy in addition to compliance issues with regard to treatment. Maintaining a regular supply of antiepileptic drugs (AEDs) is a paramount concern given the hesitation on the part of many pharmacies to issue AED based on prior prescriptions and mandating updated prescriptions for the same.

These issues pose considerable yet surmountable challenges to epilepsy care providers who may also be redeployed to shoring up pandemic services especially in public health setups. One has to anticipate the long-term effects of the pandemic on epilepsy care in terms of delays into investigation and referral, as well as management of chronic epilepsy, especially the drug-resistant forms, which may be medically managed by timely appropriate AED dose adjustments or be surgically remediable. This is likely to widen the treatment gap, thereby making it paramount that general physicians and regional neurologists take over the onus of investigating, managing, and initiating prompt referral through telemedicine or online networking with tertiary or quaternary referral centers. In India, up to 30 to 40% of epilepsy cases in children and adults may be due to the consequence of perinatal insults, parasitic, and other infections, with COVID-19 also associated with a potential of meningoencephalitis, including acute necrotizing hemorrhagic encephalitis and hypoxic encephalopathy, with resultant presentation as acute symptomatic seizures.¹ In the elderly with the potential neglect of non-communicable diseases such as cerebrovascular disorders, diabetes, coronary artery disease, chronic renal, and hepatic dysfunction, presentation of patients with encephalopathy and acute symptomatic seizures are also likely to compound and neurological services will have to be geared up for this eventuality. Immunizations against infections may also be

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delayed, which can lead to a rise in bacterial/viral infections among children compounding the risk of central nervous system complications. This is a result of the fact that preventive measures are likely to fall behind during this pandemic due to the lack of resources as well as fear in the community with regard to travel for access to health care. The high prevalence of communicable diseases such as HIV (human immunodeficiency virus) infection, tuberculosis, malaria, dengue, and cysticercosis will also provide another element to the strife especially among the lower socioeconomic strata who are already crippled by restrictions imposed in afflicted cities and towns, unemployment, and substance abuse. Although most of these patients do not have epilepsy, they have a higher risk of delayed presentation and consequent morbidity and mortality, as well as drug resistance, and health care providers will have to brace for a surge in neurological sequelae as well as presentations of epilepsy in this group of patients with communicable disorders. Active surveillance by the existing public health machinery for these disorders is paramount to prevent a systematic neglect as well as an explosion of these cases during and after the pandemic.

Recent recommendations of a multinational group of experts involved in epilepsy care are very pragmatic.² Emphasis ought to be placed on delivery of epilepsy care to the doorstep using internet-based or telecom-based telemedicine or smartphone-based hospital-sourced services as much as possible to mitigate the risk of exposure both ways, which is likely during visits to consulting chambers, outpatient clinics, and ERs. It would be desirable for each patient to have an individualized emergency rescue plan (e.g., midazolam through buccal/nasal routes, rectal diazepam, or oral clobazam). The technique for administration as well as helplines for ambulances or paramedical care in the event of lack of cessation of seizures within 5 minutes should be accessible. Viral polymerase chain reaction (PCR)-based testing facilities should be readily available in centers catering to care of children with fever-provoked seizure exacerbations, febrile status epilepticus, and Dravet syndrome as the child and guardian will have to be tested during ER visits as well as prior to indoor care in regions where community transmission is apparent. Concerns of asymptomatic carrier rates of SARS-CoV-2 mandate sentinel surveillance strategies of health care workers as well as testing of persons planned for prolonged indoor management including epilepsy surgery. Other aspects with regard to when ER visits should be sought including situations of prolonged encephalopathy or intolerable AED-related side effects such as idiosyncratic reactions or drug toxicity should be counselled beforehand. Emergent airway and respiratory support measures in children/adults with underlying disabilities or on polypharmacy in view of drug-resistant epilepsy, who are at a risk of respiratory depression (with an inherent SUDEP [sudden unexpected death in epilepsy] risk) after repetitive or prolonged seizures, have to be taught. A regular supply of AED should be made the rule, and repeat prescriptions should be readily downloadable or medications be supplied for a longer duration than usual, although needless stockpiling is to be avoided. Patients who access free supply of medications from health

centers need to be either granted an extended supply or seek door-to-door access through ASHA (Accredited Social Health Activist) workers and other panchayat support staff. Amidst all the panic, the importance of compliance is to be reiterated. Unless compelled by situations such as West syndrome, drop attacks, recurrent admissions for repetitive seizure clusters, status epilepticus, progressive encephalopathy as in Rasmussen's encephalitis or epileptic encephalopathy as a consequence of a potentially surgically remediable syndrome, dynamic interventions that are curative or palliative can be postponed (e.g., epilepsy surgery). Neuroimaging should also be delayed unless there are urgent diagnostic or therapeutic decisions to be taken, for example, new-onset epilepsy unclassified, appearance of neurological deficits, suspected increase in size of a causative tumor, bleed, traumatic injury, or infective etiologies. In parallel, diagnostic electroencephalogram (EEG) can be delayed unless nonconvulsive status epilepticus or epileptic encephalopathies such as West syndrome and epileptic aphasia spectrum disorders such as continuous spike-wave discharges of sleep are suspected. At the same time, attempts at AED reduction/cessation ought to be postponed or reversed till regular monitoring or rescue access is possible. With psychosocial stress emerging as a key after-effect of the pandemic, the importance of lifestyle is to be emphasized including avoidance of sleep deprivation, substance abuse, and promotion of digital hygiene (especially in patients with reflex epilepsy such as photosensitivity), as well as home-based recreation and relaxation techniques. This would enable the physician to address comorbidities such as depression, bipolar disorder, and psychosis.

Telemedicine-based contact, as mentioned previously, will help in addressing anxiety and management issues of patients and caregivers and instill confidence for further follow-up. For new evaluations of persons with epilepsy, careful history and smartphone or home-camera based record of events will be of immense value. Didactic "teleneurology" services, although requiring a paradigm shift in the attitude of physicians and patients/carers to enable wider acceptance, should enable reliable assessment of mentation, cognition, focal deficits, eye movements, gait, and overall disability. Hospitals should frame policies to reduce exposure of health care workers as well through staff rotas including that of neurologists and technologists, which will also facilitate contact tracing and ensure a reserve pool of health care workers. Critical care unit management of epilepsy emergencies such as status epilepticus has its own share of risks in terms of airborne spread of infection, and dedicated COVID-19 isolation units distinct from neurocritical care units are advisable to reduce direct exposure of health care professionals. Besides social distancing and disinfection policies, establishing boundaries of contact, promulgating hygiene, and observance of barriers through an effective public and protocol-driven health care worker education program will be crucial. Establishing predesignated staff and clinic spaces will facilitate tracing of contacts and minimize disruption should individual health professionals become infected. In managing status epilepticus, additional precautions should be undertaken to prevent airborne spread from secretions,

as well as timely decision-making to stepdown units and early but planned discharge to home care. Despite the constraint of resources, through a concerted effort supported by state policy, shoring up infrastructure, cooperation between public and private health care providers, and educating and empowering persons with epilepsy as well as their carers should enable all stakeholders to circumvent the odds.

In most epidemics, postmortems have contributed greatly toward the elucidation of the underlying pathophysiology of disease. Similarly, in the COVID pandemic too, despite the hazards imposed, thanks to a courageous group of pathologists, there is a rapidly growing body of literature from Italy, United States, Germany, United Kingdom, China, and so on, demonstrating that the basic pathology is endothelial damage activating both coagulation and inflammatory cascade, producing microthrombotic pathology and acute respiratory distress syndrome pathology in the lungs and other viscera. The ACE2 (angiotensin-converting enzyme 2) that is now known to be the target receptor for SARS-CoV-2 is expressed in glial cells and neurons in the brain, making it a potential target of COVID-19. Entry into the brain can occur either through hematogenous spread or through the transcriiform route. Anosmia, hypogeusia, and respiratory failure have been attributed to the direct involvement of olfactory tracts and brain stem. Other complications including acute stroke and Guillain–Barre’s syndrome have been attributed to parainfectious, postinfectious immune-mediated pathology, and hypercoagulable states. While few report presence of the

virus in cerebrospinal fluid, not many have been able to conclusively demonstrate the presence of the virus in the brain tissues examined. The relative contribution of virus versus host response in disease causation remains to be elucidated, and the final answers would need more postmortem studies, but the emerging understanding of molecular biological and immunological perturbations has provided insights into the pathophysiology of COVID-19, thereby directing treatment strategies.

To conclude, the real impact of this ongoing pandemic on people living with epilepsy will only be known in future. But the nonmedical issues such as those occurring due to loss of jobs, nonavailability of medications or lack of proper medical consultations due to lockdown, suboptimal care, poor access to telemedicine for majority of the cases, postponement of tests or interventions in selected cases, and mental health issues among others will definitive have a negative effect including widening of treatment gap for some time.

Conflict of Interest

None declared.

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