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RESEARCH ARTICLE

COMPREHENSIVE EPILEPSY CARE DURING THE LOCKDOWN DUE TO COVID-19 PANDEMIC IN INDIA: "EPILEPSY FOUNDATION INDIA MODEL."

Nirmal Surya^{1,*}, Hitav Someshwar², Balaji Patil³, Divyasiny Sharma⁴, Aarti Sharma⁵, Mangal Kardile⁶ and Janvi Someshwar⁷

¹Neurologist, Founder Trustee & Chairman, Epilepsy Foundation India, Mumbai, Maharashtra

²Physiotherapist, Epilepsy Foundation India, Epilepsy Foundation India, Mumbai, Maharashtra

³Head Medical Affairs, Eisai Pharmaceuticals India Pvt Ltd

⁴Yoga Instructor, Epilepsy Foundation India, Epilepsy Foundation India, Mumbai, Maharashtra

⁵Psychologist, Epilepsy Foundation India, Epilepsy Foundation India, Mumbai, Maharashtra

⁶Cognitive therapist, Epilepsy Foundation India, Epilepsy Foundation India, Mumbai, Maharashtra

⁷Occupational therapist, Epilepsy Foundation India, Epilepsy Foundation India, Mumbai, Maharashtra

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ABSTRACT

As we are facing a critical pandemic since last 2.5 months. This pandemic not only impacted the financial and social life of people but made us change the conventional way of managing patients. This pandemic created a completely new normal for the world, and to face this new normal, we required a completely new armament to face challenge of pandemic. Epilepsy Foundation is NGO from Mumai India. From long time, Epilepsy Foundation dedicatedly worked for People with Epilepsy who are not able to get the comprehensive care. Now, in this Pandemic, Epilepsy Foundation created innovative model for comprehensive care of Epilepsy. This module not only provides the Pill and pill related services but, this module enables to provide a comprehensive care for patients which includes Yoga, Physical Therapy, Cognitive therapy and occupational therapy and Quality of life of patient. This module designed by keeping in mind the social distancing aspects of Pandemic and new normal of world.

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INTRODUCTION

There have been a great many major epidemics in the recent past. This includes, to name but a few, Ebola, Zika, dengue, chikungunya, acute flaccid myelitis and H1N1 influenza. Separate from SARS-CoV2. It's just hit us! And that's very fast (Huang, 2020). It emerged around December last year in the Wuhan region of China, and by April gripped over a hundred countries (Rothan, 2020). According to Reports, as of 15th June, 2020 (83rd Day of Lockdown), With over 11,500 fresh cases reported in last 24 hours, Covid-19 infections in India on Monday rose to 3.32 lakh, with the death toll approaching the 10,000 mark. As per the latest Health Ministry, the toll stood at 9520, with the recoveries more than the active cases. While nearly 1.7 lakh people have recovered, there are over 1.5 lakh active infections in the country (Gettleman, 2020)

*Corresponding author: Nirmal Surya,
Neurologist, Founder Trustee & Chairman, Epilepsy Foundation
India, Mumbai, Maharashtra.

Impact of Lockdown on Health Care system: Public transit has halted all but one. Personal travel, and even venturing from homes on foot, is discouraged for virtually every reason except in connection with the procurement of medicines, medical needs, and emergency services. A significant number of patients with chronic Neurological illnesses, such as Epilepsy, Parkinson's disease, Headache, Dementia etc, have had trouble accessing hospitals. Most private clinics and outpatient departments in hospitals are closed or working at a capacity of less than 25%. Moreover, almost all medical services in hospitals have been centralized in the care against COVID-19. As a result, the diagnosis and treatment of these patients were severely delayed.

Covid 19 and Epilepsy: As per CDC Statement Epilepsy could be a risk factor for COVID-19 although we don't have enough evidence to determine this association. Initially, the main concern with COVID-19 was thought to be pneumonia however emerging evidence are suggesting that

central nervous system might be a possible target because the angiotensin -converting enzyme two receptors are detected on the surface of glial cells and neurons. We do not currently have enough evidence to indicate the severity of the pandemic of Epilepsy and COVID-19. However, the fever associated with COVID or due to lock-down financial or emotional stress could be the trigger factor for seizures. Restricted movement and anxiety may result in non-adherence to anti-epileptic drugs, drugs used for COVID may have interactions with anti-epileptic drugs, and the new introduction of anti-epileptic drugs such as everolimus that influence the immune system.⁽⁵⁾ Overall, the COVID -19 and related ecosystem might put the extra burden on people with epilepsy. This increase of burden requires extra care for people with epilepsy. India has been in Lock down for more than two months and patients are being deprived of basic care. This ecosystem creates an imbalance between care that could hinder the stability of people with epilepsy or worsen epilepsy, psychiatric problems and the overall quality of life.

Epilepsy Foundation India: The Epilepsy Foundation India started in 2009 as a NGO in Mumbai with the intent of providing comprehensive care, awareness, inculcating to address the misconception and stigma surrounding this disorder, providing affordable healthcare and rehabilitation to patients with epilepsy, creating irrespective of their gregarious stature, accommodating the vulnerable in India's most remote area.

Epilepsy Foundation India Activities

Urban OPD: The NGO holds weekly Epilepsy OPD on Tuesdays for the needy patients. Multidisciplinary care is provided throughout the week, Neurology consultations, physical therapy, occupational therapy, Psychological counselling, Cognitive therapy, Yoga, Dance therapy, Music therapy & Vocational therapy. Monthly Rural Camps: Epilepsy Foundation conducts rural camps as Public Private Partner since 2011 in Association with National Health Mission government of Maharashtra. The purpose of rural camps is to offer comprehensive treatment to People with Epilepsy in rural districts of Maharashtra. During the camp consultation by Neurologist, Neurosurgeons, Paediatricians along with Physical therapist, occupational therapist, Speech & Language Pathologist, Psychologist & cognitive therapist. The patients are educated about the conditions, the society is made aware about the conditions along with removing the myths of the condition. They are provided by free medications also for a period of 3 months. (Figure 2)

Social Activities: The goal of educating and removing from society stigma about Epilepsy. The Epilepsy Foundation offers instructional content, street play arrangements, patients, and related education. Educational Activities: The goal is to provide physicians, nurses and technicians with the updated information. The Epilepsy Foundation organizes ongoing medical education event to promote the updating of doctors, nurses and technicians ' expertise.

Data integration and follow-up: The goal is to provide a constant understanding of the illness profile of the individual with Epilepsy. The basis for epilepsy began with the digital Epilepsy mobile app to collect information on Epilepsy and different aspects.

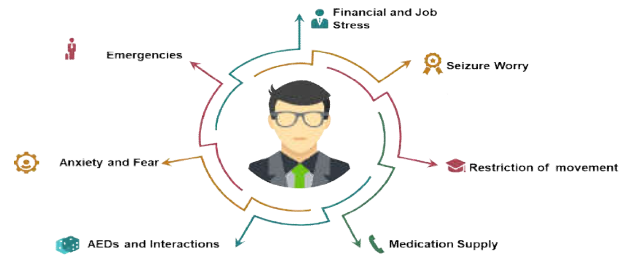


Figure 1. Person with Epilepsy and Challenge due to COVID Pandemic

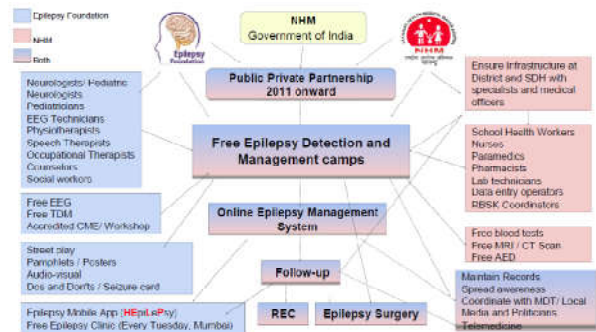


Figure 2 Epilepsy Foundation Model6

Epilepsy Foundation India and COVID: At present there is no evidence present which has proved that patients with epilepsy are at a higher risk of contracting COVID-19. Similarly, there is no evidence of any anti-epileptic drug interactions with the treatment of COVID-19. In our centre, our OPD foot drop is reduced by 75%. As a result of limits on movement patients have begun to be deprived of access to medication and adequate epilepsy treatment. In response to this challenge, we have developed a management model for patients with epilepsy that has been shown to be highly consistent with the latest modifications of clinical activities due to the pandemic.

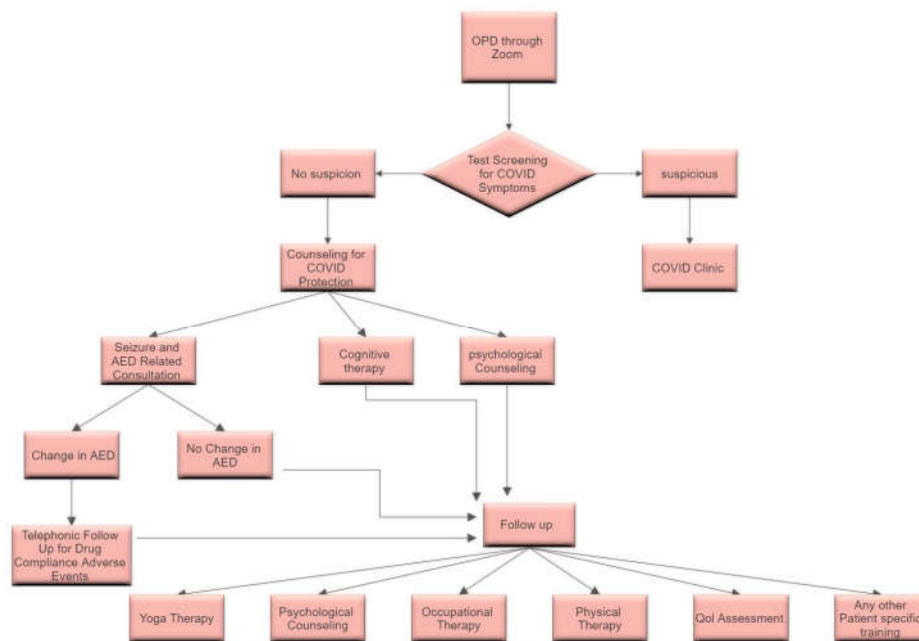
Teleconsultation & Telerehabilitation by Epilepsy Foundation India

Setting up the Model: The Epilepsy Foundation reviewed the HIPAA Compliance Guidelines and carried out a feasibility check for the Platform based on patient comfort, access, and HIPAA complaint. This new modality will allow us to provide this comprehensive treatment without a compromise on quality. Based on our needs, we choose ZOOM application as an acceptable choice.

Consent: For every remote consultation, patient consent has been taken through electronic media.

Epilepsy Foundation India Digital Model

Consulting and regular follow up on every Tuesday: The patients enrolled with the NGO would follow up with the neurologist as per the advice of the Neurologist. Some patients visit the neurologist once a week, once in 15 days or once in 1 month depending upon the severity and control of epilepsy. Due to minimum movement and maintenance of social distancing we started consulting patients online on various online based applications which were available with the patients.



A few serious patients who had an increase in their seizure frequency were checked in person by the neurologist following the guidelines provided by the Ministry of Health and Family welfare for treating of Non-Covid patients during the lockdown. Telephonic consultations were provided to those patients who couldn't connect via online applications for video consultation. The patients were advised to consult via telemedicine and not rush to the hospitals if they had one episode of seizure of a small duration or any side effects related to medicines.

Consultation Type	Consulted Patient on Zoom
Neurologist Consultation	168 (17*)
Cognitive Therapy	49
Yoga Session	142
Psychological Counselling	38 (6*)
Physiotherapy	53
Occupational therapy	53
Telephonic Consultation	58

*Patients called in Clinic when ZOOM Consultation did not resolve the patient issues.

Availability of Anti- Epileptic Medications: Majority of the Anti- Epileptic medications are provided on basis of prescription and the date till which it needs to be prescribed. A few of our patients faced this problem as the date on the prescriptions had been expired. The NGO had requested the local authorities to direct pharmacists to provide medication on the prescriptions which had expired. Also, where this wasn't possible the NGO after tele consultation of the patient with the neurologist provided a prescription to the patients with the changes as advised by the neurologist as an electronic version. The foundation provided free medications to the needy patients again by maintaining social distance and other protective measures as advised by ministry of health and family welfare. Advise to stock up medications were issued to the patients as missing even a single dose poses a threat for seizures.

Therapy sessions for Neuro-disability associated with Epilepsy

Yoga therapy: Yoga therapists provided online group yoga sessions every Saturday under supervision for 1 hour; the patients were advised to follow practicing yoga for 5 days a week, 1 hour daily.

Since yoga is known to reduce the EEG activity, reduce emotional stress and reduce seizures (Streeter, 2012).

Counselling: Clinical psychologists provided one on one counselling every Thursday to reduce the anxiety and stress related to Epilepsy and covid 19 Pandemic. There are reports which suggest a reduced quality of life due to the lockdown as well as the stigma associated with the Epilepsy and COVID19 has been reported (Nirmal Surya and Hitav Someshwar, 2019; Ngugi, 2010) Hence Counselling is of utmost importance to reduce the psychological and social co-morbidities. The patients and the relatives were counselled to reduce screen time, have a proper sleep schedule & also maintaining self-hygiene (Someshwar, 2020).

Cognitive therapy: Cognitive therapist also provided one on one cognitive therapy sessions for the patient every Friday, during that session the therapist trained the family members on how to conduct cognitive therapy for the patients and how to progress. The care givers were asked to continue therapy at home for 3-5 days a week. Inclusion of family in rehabilitation is the main stay and the need of the hour, to reduce the burden on the rehab professionals and also to match the supply and demand of qualified persons in a developing country like India. (<https://www.unicef.org/documents/social-stigma-associated-coronavirus-disease-covid-19>).

Occupational and Physical therapy- They were also provided by trained therapist to patients who had physical & behavioural co-morbidities thru online consultations Every Thursday under online supervision and the patients were advised to continue the same for 2-3 times per day for 4-5 days per week. Patients were even given online advice for aerobic exercise to maintain cardiopulmonary endurance and keep a control on increase in weight. Majority of the anti-epileptics are titrated based on the patient's body weight, an increase in the weight will lead to an increase in the dose on medications for controlling seizures (Lukersmith, 2013; 14)

Implication of this Model: With this digital model, we are able to develop a highly successful and detailed Epilepsy patient model. We have been able to provide patient follow-up services free of charge for the last 2 months.

DISCUSSION

The WHO advises incorporating the effective use of health telematics into the overall health policy and plan for all in the 21st century. In order to improve and disseminate information and epilepsy awareness, the development of information technology offers. The Epilepsy Foundation Model provides a capacity in this lockdown situation, where healthcare personnel and services are not readily accessible, to enhance the quality of management and increase the satisfaction of patients and carers. Through our personal experience we would like to put forth that the number of consultations has reduced significantly (Approx 10%). The main reason for this can be incompatible mobile phones, lack of digital knowledge, fear, poor connectivity & social stigma. These shortcomings will be overcome in due course of time. However, those who were able to connect have been compliant to the activities organised by the foundation. Epilepsy foundation India would like to transfer this digital model practiced in an urban set up to the rural population of Maharashtra so as to benefit people living with epilepsy in rural districts of Maharashtra. Through these practices we urge the other professionals working in this field to Epilepsy to Manage and rehabilitate persons with epilepsy during these trying times of COVID 19 pandemic through either tele or video consultations techniques for the better prognosis of our patients. None the less telemedicine has its own pros and cons, valuable consultation and support from the health care workers can go a long way in improving quality of life in our patients. Improvement in the awareness of tele-neurology & telerehabilitation will help in reducing the cons to some extent. The patients though not a high-risk population need to be advised to follow the advice by World Health organization & Ministry of Health and Family welfare for maintaining hand hygiene, social distance & reporting any Flu like symptoms to the concerned authority. Caring for the patients of epilepsy who have been subjected to social stigma, psychological and emotional comorbidities, at this time will help in reducing the additional stigma associated with COVID-19 and the psychological and emotional stress associated secondary to lockdown (Ngugi, 2010)

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