

Impact of COVID-19 on People Suffering with Epilepsy

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Abstract

Background: Epilepsy is one of the most common problems in neurology clinical practice and currently we are in the midst of the coronavirus outbreak. The coronavirus pandemic is an epidemiological and psychological crisis, which is likely to affect persons with epilepsy. **Objectives:** This study was designed to evaluate the impact of COVID-19 pandemic on patients with epilepsy and effects on their mental health. **Materials and Methods:** This was a cross-sectional web-based survey carried out at the department of Neurology at a tertiary care hospital. A questionnaire was designed in the local language using Google Forms to assess basic knowledge regarding epilepsy, coronavirus, effects of COVID-19 and lockdown on epileptic patients and also effects on their mental health. The link to the online survey was distributed via WhatsApp messenger to epilepsy patients. **Results:** One hundred fifty-six cases were enrolled with 69.1% were below 34 years of age and male: female ratio was 1.2:1. Only 34.3% of the participants were employed and 50% of patients had an income of less than Rs. 3000 per month. Of the patients enrolled, 20.5% reported the “devil” and superstitions as a cause of epilepsy and only 10% of patients thought that tantric (holy priest) could treat the disease better than doctors. 53.8% of patients worried about getting COVID-19 and could not stop thoughts about being infected by coronavirus bothering them. 30.3% patients had increased seizure frequency during COVID-19 pandemic, of which the most common reason was that they forgot to take regular antiepileptic drugs (22.7%) or they had faced difficulty in obtaining medicine due to lockdown (12.1%). During the pandemic, 17% of patients reported depression symptoms and another 21% reported anxiety symptoms. **Conclusion:** The current COVID-19 pandemic negatively affected patients with epilepsy and increased seizure frequency, depression, anxiety, unemployment, and financial difficulty in obtaining medication.

Keywords: Anxiety, COVID-19, depression, epilepsy, seizure, survey

INTRODUCTION

Epilepsy is the most common serious neurological disease affecting over 50 million people worldwide and an estimated 10 million plus people in India. The prevalence is higher in the rural (1.9%) as compared to urban population (0.6%).^[1]

Coronavirus disease 2019 (COVID-19) is a novel infectious disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and the outbreak which initially occurred in Wuhan, China in late 2019, is now rapidly spreading globally. In March 2020, WHO characterized COVID-19 as a pandemic.^[2]

Current COVID-19 pandemic has created panic in the whole world because the virus is very contagious and there is no effective drug or vaccine against it till date. Complete lockdown during COVID-19 and restriction of movement, social distancing, and changes in lifestyle had resulted in psychological stress and depression in public at large.^[3] Stress reactions can include low or depressed mood, anxiety, frustration, irritability, anger, and social isolation.^[4]

At present, there is no information to suggest that either epilepsy or its treatment (antiepileptic drugs) will in any way make a person susceptible to COVID-19.^[5,6] Indeed, there is no suggestion that people with epilepsy have any special immune vulnerability either to COVID-19. However, the stress of the pandemic can induce sleep deprivation and lifestyle changes and can make a person prone to increase in the frequency of existing seizures.

We conducted an online survey to study the effects of COVID-19 among patients with epilepsy. This survey consisted of questions regarding knowledge about epilepsy, coronavirus, effects of COVID-19 and lockdown on patients with epilepsy and also, effects on their mental health.

MATERIALS AND METHODS

This was a cross-sectional web-based survey carried out by the department of Neurology of a tertiary care hospital attached to a medical college. Already diagnosed cases of epilepsy were recruited in the study after taking written consent. A questionnaire was designed in the Hindi language using Google Forms (developed by Google) to assess basic knowledge regarding epilepsy and coronavirus and the effects of the COVID-19 epidemic and lockdown on epilepsy and

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mental health of patients. The link to the online survey (Google Form) was distributed via WhatsApp messenger to epilepsy patients. A screening question was used to filter out patients with epilepsy from the normal persons in the community and those who responded positively participated in the survey. Link to the online survey was also directly forwarded by the researchers among known patients with epilepsy using other social media platforms and short message service (SMS). Total anonymity was maintained and respondents could fill the survey through the predesigned questionnaire only once. All questions were mandatory in the survey. One hundred fifty-six participants took part in the study out of which only 134 patients had epilepsy. Of these, two participants declined to give consent and were excluded from the study.

Survey instrument

After reviewing several survey instruments about knowledge, attitude, and practice (KAP) studies used by other groups studying epilepsy and coronavirus,^[2,7] we developed a 41-item questionnaire. The questionnaire mostly comprised closed-ended questions to which the responses were either “Yes” or “No.” The questionnaire was divided into four sections. Section I requested demographic information including residence, age, gender, marital status, educational level, occupation, family structure, and monthly family income (8 items); Section II investigated the level of knowledge of epilepsy (6 items); and Section III and IV explored the effects of COVID-19 on epilepsy (14 items) and effects of COVID-19 on mental health (13 items) of patients with epilepsy. The data was collected in the first fortnight of May 2020.

Modified Kuppaswamy socioeconomic scoring of educational qualification, occupation, and monthly income of family was used for the study.^[8]

This project was approved by the institutional ethics committee. The study was conducted in accordance with the Helsinki declaration on research ethics. Participation was voluntary and the responses were anonymous.

The data was analyzed using SPSS version 20.0. The demographic data and knowledge were analyzed using descriptive statistics (mean, percentage, and frequency distribution).

RESULTS

One hundred thirty-two patients with epilepsy participated in the study. All patients belonged to the state of Rajasthan. Mostly (57.1%) belonged to rural areas.

The demographic profile is shown in Table 1. Most of the cases were within the age group of 25–34 years. The study population consisted of 55.8% male and 44.2% female patients, with male:female ratio of 1.2:1.

A total of 65.6% patients had basic education, whereas 34.4% patients were either graduates or postgraduates.

Only 34.3% were employed. 26% got unemployed recently due to COVID-19 pandemic. 63.6% of cases were from the low socioeconomic class with 49.3% of patients with an income of less than Rs. 2390 per month.^[8]

As shown in Table 2, 79.5% of the patients believed in the organic brain etiology as the cause of epilepsy; however, 20.5% believed that the “devil” and superstitions were the cause. 95.5% of people believed that epilepsy was not a contagious disease and was curable with medication. Majority of the patients (90.2%) considered treatment from doctors to be much better than faith healers/quacks.

Table 1: Demography details of participants (n=154)

S.No.	Questions	No. of patients (%)
1.	Where do you live?	
a.	Rural	88 (57.1%)
b.	Urban	66 (42.9%)
2.	What is your age?	
a.	18-24 years	50 (32.5%)
b.	25-34 years	56 (36.4%)
c.	35-44 years	40 (26%)
d.	45-54 years	4 (2.6%)
e.	>55 years	4 (2.6%)
3.	Sex	
a.	Male	86 (55.8%)
b.	Female	68 (44.2%)
4.	Occupation	
a.	Government service	10 (6.5%)
b.	Private Service	13 (8.4%)
c.	Retired	9 (5.8%)
d.	Housewife	27 (17.5%)
e.	Student	29 (18.8%)
f.	Self-Employment	13 (8.4%)
g.	Other Services	17 (11%)
h.	Unemployed	40 (26%)
5.	Education	
a.	Till 12 th	101 (65.6%)
b.	Till graduation	40 (26%)
c.	Up to post graduation	13 (8.4%)
6.	Family structure	
a.	Joint family	112 (72.7%)
b.	Nuclear family	42 (27.3%)
7.	Marital status	
a.	Single	68 (44.2%)
b.	Married	69 (44.8%)
c.	Divorced	2 (1.3%)
d.	Apart	15 (9.7%)
e.	Widow	-
8.	Monthly Family Income	
a.	Rs 47438 and above	4 (2.6%)
b.	Rs 23674-47437	9 (5.8%)
c.	Rs 17756-23674	12 (7.7%)
d.	Rs 11837-17755	16 (10.3%)
e.	Rs 7102-11836	16 (10.3%)
f.	Rs 2391-7101	21 (13.6%)
g.	Less than Rs 2390	76 (49.3%)

Effects of COVID-19 on epilepsy are shown in Table 3. All patients had heard about coronavirus and were acquainted with its symptoms. 53.8% of patients worried about getting COVID-19 and could not stop thoughts about being infected by coronavirus bothering them. 50.8% of patients were afraid of COVID-19 and 15.9% thought that they had been infected by coronavirus, despite being reassured by other people to the contrary.

30.3% of patients had increased seizure frequency during COVID-19 pandemic. The most common reason cited was that they forgot to take regular antiepileptic medicine (22.7%) or they had faced difficulty in obtaining medicines due to lockdown (12.1%). Majority of patients (71.9%) had consulted their doctors by going to a hospital and only 28% of patients had used telemedicine facility to consult a physician. 55.3% of patients also reported to have faced problems in obtaining medicine due to lack of money. 64.4% of patients were afraid of going to the hospital and 61.4% had faced difficulty in reaching the hospital.

Table 2: Questions related to knowledge of epilepsy (n=132)

Questions	Yes	No
Is epilepsy an organic brain problem?	27 (20.5%)	105 (79.5%)
Can epilepsy spread by contact?	6 (4.5%)	126 (95.5%)
Does an epileptic patient need lifelong treatment?	17 (12.9%)	115 (87.1%)
Can epilepsy be cured?	122 (92.4%)	10 (7.6%)
Do you think tantric (holy)/ priest can treat epilepsy better?	13 (9.8%)	119 (90.2%)

Effects of COVID-19 on the mental health of patients with epilepsy are shown in Table 4. The coronavirus pandemic has been assumed to cause increased psychological issues but interestingly, we were not able to observe any significant effect of COVID-19 pandemic on patients with epilepsy. 17% of patients reported depression symptoms and 21% reported anxiety symptoms. Overall, 25 (18.9%) participants admitted that the COVID-19 pandemic had significantly affected their personal, social, and occupational life in some ways in a negative manner.

DISCUSSION

Epilepsy is one of the most common problems in neurology clinical practice. The current COVID-19 pandemic is an epidemiological and psychological crisis. The atrocity of living in isolation, changes in our daily lives, unemployment, financial hardship, and grief over the death of loved ones have the potential to affect the mental health and well-being of patients with epilepsy.

This study was designed to evaluate the impact of COVID-19 epidemic on patients with epilepsy and to the best of our knowledge is a first such study in Indian patients with epilepsy.

All the participants in the study were from Rajasthan mostly from a rural area with male preponderance, which is comparable to other studies.^[9,10] The male preponderance can be explained with hiding of facts by the parents due to social stigma associated with female gender and disease.

Age analysis in our study shows a higher prevalence in young adults.^[9] The lower prevalence rate of epilepsy in the elderly in

Table 3: Effects of COVID-19 on different features of epilepsy (n=132)

S.No.	Questions	Yes	No
1.	Do you know about the corona pandemic?	132 (100%)	-
2.	Do you think and worry about corona disease all day?	71 (53.8%)	61 (46.2%)
3.	Are you able to stop the thoughts related to Corona from constantly coming and bothering you?	101 (76.5%)	31 (23.5%)
4.	Are you afraid of corona disease?	67 (50.8%)	65 (49.2%)
5.	Do you fear that coronavirus has infected you, despite being persuaded by other people?	111 (84.1%)	21 (15.9%)
6.	Do you think that epileptic seizures may increase due to corona?	40 (30.3%)	92 (69.7%)
7.	Have you had any epileptic seizures since the onset of corona disease?	30 (22.7%)	102 (77.3%)
8.	What do you think was the reason for these (corona epidemic since its inception) seizures?		
a.	Forgot to take medicine	30 (22.7%)	102 (77.2%)
b.	Nonavailability of medicines due to lockdown	16 (12.1%)	116 (87.8%)
c.	Due to sleeplessness	6 (4.5%)	126 (95.45%)
d.	Due to concern of corona pandemic	4 (3%)	128 (96.9%)
9.	Is there a problem with the drug being available due to the lockdown?	82 (62.1%)	50 (37.9%)
10.	How did you consult a doctor during this time regarding epilepsy?		
a.	Going to the hospital	58 (43.9%)	74 (56.06%)
b.	By showing yourself to the same doctor	37 (28%)	95 (71.9%)
c.	Via telemedicine (via phone, video call)	37 (28%)	95 (71.9%)
11.	If you consulted through telemedicine, was there any problem?	28 (21.7%)	104 (78.3%)
12.	During this time, due to lack of money, was there any difficulty in getting medicines?	73 (55.3%)	59 (44.7%)
13.	Are you afraid of going to the hospital because of corona disease?	85 (64.4%)	47 (35.6%)
14.	Did you have trouble reaching the hospital because of the lockdown?	81 (61.4%)	51 (38.6%)

Table 4: Effects of COVID-19 on mental health of patients with epilepsy (n=132)

Questions	Yes	No
Are you suffering from any mental illness in the past?	17 (12.9%)	115 (87.1%)
Are you currently receiving treatment for a mental illness?	22 (16.7%)	110 (83.3%)
Are you suffering from any chronic illness (such as hypertension, diabetes, asthma, arthritis, etc.)	9 (6.8%)	123 (93.2%)
Do you have problems sleeping these days?	26 (19.7%)	106 (80.3%)
Has your appetite changed much these days?	41 (31.1%)	91 (68.9%)
Does your mind remain mostly depressed for the last 2 months?	23 (17.4%)	109 (82.6%)
Do you feel tired most of the time for the last few days?	30 (22.7%)	102 (77.3%)
Don't you feel sad in life for the last few days?	27 (20.5%)	105 (79.5%)
Do you feel uncertain about the future?	27 (20.5%)	105 (79.5%)
These days, do you worry most of the time?	29 (22%)	103 (78%)
Do you often feel tremor or tension in the body?	27 (20.5%)	105 (79.5%)
Do you feel lacking in concentration to do any kind of work?	27 (20.5%)	105 (79.5%)
Have any of the above symptoms affected your personal, family, social, or professional life?	25 (18.9%)	107 (81.1%)

developing countries may be related to multiple factors such as lower life expectancy, higher seizure-related mortality, and under assessment of seizure disorders in this population.^[9,10]

In the present study, most of the patients had received some form of education and there were only few who were undergraduates or postgraduates. All patients could read and write Hindi. This clearly indicates that epilepsy is no longer a hindrance to acquire education and similar results were reported in other studies. It is also consistent with improving literacy rate in Rajasthan (66.1% as per 2019 census).^[11]

Most of the patients with epilepsy in our study were unemployed. The coronavirus crisis has led to a spike in the country's unemployment rate which is comparable with our study (27.11% in May 2020 as per CMIE India).^[12]

In the study, basic knowledge of patients with epilepsy was found to be similar to another study from India.^[10,13] About the cause of epilepsy, majority patients with epilepsy thought it to be an organic brain problem while few still believed it to be due to the "devils" and evil spirits.

Data from our survey suggested that most respondents believed epilepsy to be curable and they would prefer treatment by doctors over faith healers/quacks in contrast to previous studies.^[14]

All participants had heard of the coronavirus (COVID-19), due to widespread media coverage and government awareness programs.

More than 50% said that they were "worried" and "afraid" about getting the coronavirus. Very few patients (15.9%) believed that they would definitely or probably get the coronavirus, despite being convinced by other people to the contrary.

At present, there is no information to suggest that either epilepsy or its treatment will in any way make a person susceptible to COVID-19. Still, 30.3% patients had reported increased seizure frequency during COVID-19 pandemic, which could also be due to patient missing his regular medication, sleep deprivation, or due to shortages of supply of medication because of nation-wide lockdown.

Current COVID-19 pandemic and governmental measures of lockdown, social distancing, and self-isolation have complicated the management of patients with neurological chronic diseases by causing or worsening concomitant anxiety and depression, hampering the contacts with physicians.

In our survey, many patients were having a past history of psychiatric illness and are currently taking psychiatric treatment. Many of the participants reported a significant change in appetite and had disturbed sleep.

The lifetime prevalence of depression in epilepsy has been estimated at between 6% and 30% in general population and the global prevalence rate of anxiety disorder in general population is 5%–45%.^[15,16]

We did not observe any significant effect of COVID-19 on mood status in participants as only 23 (17.4%) of total participants reported feeling sad, about 27 (20.5%) were experiencing anhedonia and 30 (22.7%) reported experiencing significant fatigue. A possible explanation for this finding could be because all the patients were on antiepileptic medicines some of which also act as a mood stabilizer and antianxiety medicines.

While assessing anxiety domain, 29 (22%) participants were anxious, 27 (20.5%) were feeling uncertainty about future, and 27 (20.5%) were experiencing significant tension in their body. Approximately, 27 (20.5%) were experiencing poor concentration. Overall, about 25 (18.9%) participants admitted that the above-mentioned symptoms have significantly affected their personal, social, and occupational life in some ways in a negative sense.

Our study has some limitations. First, the data was obtained from self-reported questionnaires and was, therefore, subjective. Second, the study included a modest number of participants.

CONCLUSION

Our study suggests that the current COVID-19 pandemic causes increased unemployment, financial hardship, difficulty in obtaining medication causing a modest increase in fits, and increased depression, anxiety levels in patients with epilepsy, affecting their personal, social, and occupational life.

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Conflicts of interest

There are no conflicts of interest.

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