

Patients with Neurological Illnesses and Their Experience During the Lockdown: A Teleinterview-based Study

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Abstract

Background: Governments have imposed lockdowns in the wake of the COVID-19 pandemic. Hospitals have restricted outpatient clinics and elective services meant for non-COVID illnesses. This has led to patients facing unprecedented challenges and uncertainties. This study was carried out to assess patients' concerns and apprehensions about the effect of the lockdown on their treatments. **Materials and Methods:** An ambispective, observational cross-sectional single centre study was conducted. Patients were contacted telephonically and requested to answer a structured questionnaire. Their responses were documented and summarized as frequency and proportions. **Results:** A total of 727 patients were interviewed. Epilepsy (32%) was the most common neurological illness in our cohort followed by stroke (18%). About half the patients and/or their caregivers reported health-related concerns during the lockdown. The primary concern was how to connect with their treating neurologist if need arose. Forty-seven patients (6.4%) had drug default. Among patients on immunomodulatory treatments, only eight patients had drug default. High compliance rates were also observed in the stroke and epilepsy cohorts. Of the 71 patients who required emergency care during the lockdown, 24 could reach our hospital emergency. Fourteen patients either had a delay or could not seek emergency care. Two-thirds of our patients found the telemedicine experience satisfactory. **Conclusion:** The ongoing pandemic will continue to pose challenges to both physicians and patients. Patients in follow-up may need to be contacted regularly and counselled regarding the importance of maintaining drug compliance. Telemedicine can be used to strengthen the healthcare delivery to patients with non-COVID illnesses.

Keywords: Lockdown, non-COVID illnesses, teleneurology

INTRODUCTION

The ongoing Corona virus disease (COVID-19) pandemic has posed significant challenges to public health.^[1] As the world grapples with this unprecedented health crisis, radical measures such as countrywide lockdowns, social distancing, use of masks and sanitizers have been implemented to curb spread of the virus. The Government of India imposed a countrywide lockdown on March 25, 2020.^[2] As the number of cases dwindled, the country started inching towards normalcy only to be pegged back by the massive second wave of the pandemic. Since then lockdown has been imposed again across the country. Hospitals have again restricted outpatient clinics and elective services compromising healthcare. The brunt of this has been borne by patients with non-COVID illnesses all around the world and probably even more so developing countries, where the health services are already stretched. In India, the doctor to patient ratio is 1:1456^[3] and this is much below the World Health Organization recommended ratio of 1:1000. With hardly any data available on non-COVID patient care gap, the exact magnitude of this deficit remains speculative. As we strive to fulfill the mandate of patient-centered care, addressing patients' concerns and apprehensions about the effect of the lockdown on their treatments becomes important. This study was conducted to evaluate patients' difficulties and apprehensions about healthcare during the lockdown.

MATERIALS AND METHODS

This was an ambispective, observational cross-sectional single centre study. All patients who had been consulted via telemedicine in the Department of Neurology over a period of three months after the lockdown was enforced were contacted telephonically. Demographic data such as age, sex and place of residence were recorded along with diagnosis and treatment details. Participants were requested to answer a structured questionnaire created by investigators (PG, RB and MBS). The questionnaire aimed to capture concerns of patients during the period of lockdown. We also looked into information regarding drug availability and procurement. A question pertaining to

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drug compliance during the lockdown and questions probing emergency care requirements and patients' experience in availing emergency services during lockdown were included. Patient's perspective regarding telemedicine was documented as well. An open-ended question asking for any other concern that may not have been listed was also included. A neurologist who was not a part of the study vetted the questionnaire. The questionnaire was drafted in English. However, the interview was conducted in the local language. In case the patient had significant voice impediment or cognitive decline, the caretaker was interviewed.

Mean (\pm Standard deviation) was taken as the measure of central tendency. Data were summarized as frequency and proportions. The data set was analysed using statistical package for social sciences (SPSS, version 20.0) and Microsoft Excel.

Standard protocol approvals, registrations and patient consents

The institutional ethics committee approved the study. A verbal consent was obtained after explaining the nature of the study to patients or their relatives.

RESULTS

A total of 727 patients who had been consulted telephonically between April 1, 2020 and June 30, 2020 participated in the study. There were 431 (59.3%) males. The mean age of the patients was 39 years.

Types of neurological illnesses

Out of 727 patients, epilepsy was the dominant illness [232 (31.9%)], followed by stroke [128 (17.6%), 113 ischemic and 15 hemorrhagic] [Supplementary Figure 1]. Other conditions included neuroimmunological disorders, movement disorders, primary headaches, disorders of muscle and neuromuscular junction, central nervous system (CNS) infections, peripheral neuropathy, neurodegenerative dementia, ataxia, vascular disorders (such as CNS vasculitis, arteriovenous malformation) and miscellaneous neurological illnesses such as radiculopathy, musculoskeletal pain, etc.

Concerns during the lockdown

Among the population surveyed, 356 (49%) patients and/or their caretakers reported health-related concerns during the

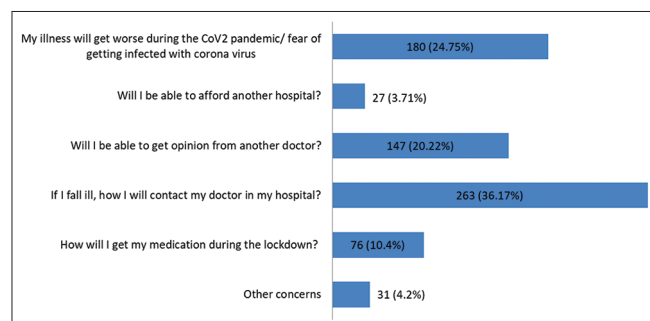


Figure 1: Patients concerns during the lockdown

lockdown [Figure 1]. The primary concern was how to connect with their treating neurologist if a need arose. Other concerns included cancellation of scheduled appointments and not knowing how to reestablish contact with the doctor and fear of worsening of their existing illness or contracting SARS CoV2 infection. Only 10.4% patients were worried about procuring their medications. Apprehension about upcoming scheduled blood tests or neuroimaging was the other major concern, which patients reported, although this item was not listed in the questionnaire [Figure 1].

Drug procurement, compliance and default

Majority of the patients and/or their caretakers (585, 80.4%) had no difficulty in procuring their prescribed medications during the lockdown period. Seventy-six (10.5%) patients had purchased and stocked it in advance. Thirty-six (4.3%) patients could not get their medications and 30 (4.1%) patients were not on any medications at the time of our phone call. Although majority (90%) of the patients were compliant to drugs, 47 (6.4%) patients had drug default [Figure 2]. Running out of medications was the most frequent cited answer as the cause of drug default with the most common reason cited being a lack of medical store in their vicinity followed by failure to obtain renewal of prescription and affordability issues. Other causes of drug default included adverse effects which they could not discuss with their physician felt it was not required anymore and fear of immunosuppression and contracting corona virus infection [Figure 2].

We specifically analysed the compliance and drug default in patients who were on immunosuppressants and immunomodulatory therapy, secondary prevention for stroke and antiepileptic drugs. Patients who are on such therapy can have relapse of the disease, recurrence of stroke or breakthrough seizures if compliance is not maintained adequately. Hence, it was important to assess adherence to drugs in such patients.

Immunosuppressant and immunomodulatory drugs

A total of 99 patients were on immunosuppressant or immunomodulatory drugs [Table 1]. The most common immunosuppressant was azathioprine. Only eight patients reported drug default [Table 1].

Drug compliance and monitoring of risk factors in stroke patients

Compliance was high among these patients with barely any drug default [Table 2]. Most of the patients monitored their risk factors including diabetes and hypertension in their homes or nearby clinic. Only three patients were on oral anticoagulation with a vitamin K antagonist, and all of them were regularly monitoring their INR. The primary reason for not monitoring their risk factors was reported to be a difficulty in accessing the health services during the lockdown. Majority of the patients (48/54, 88.9%) continued to be off smoking/tobacco and alcohol as counselled by their neurologist at the time of

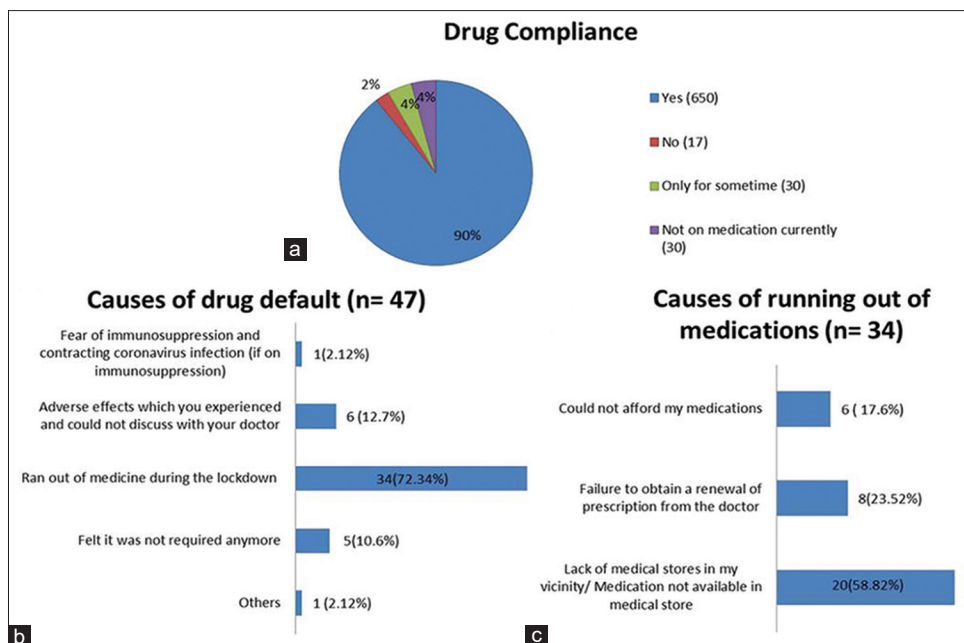


Figure 2: (a) Drug Compliance, (b) drug default and causes of default across the cohort, (c) shows the causes of running out of medications

Table 1: Immunosuppressant or immunomodulatory drugs and drug default

Immunosuppressant or Immunomodulatory drugs (n)	Drug default (n)
Azathioprine	49
Mycophenolate Mofetil	10
Rituximab	10
Dimethyl Fumerate	9
Teriflunomide	3
Steroids alone	10
Others	8
Total	99

stroke. No resumption of smoking or alcohol use was observed in these patients.

Drug compliance in patients with seizure disorder

Out of a total 232 patients, 222 (95.2%) were taking antiepileptic drugs regularly. Only eight patients were not compliant to their therapy. Two patients were not on any antiepileptic drugs at the time of our phone call.

Emergencies and problems encountered

In our cohort, 71 (9.7%) patients required emergency care during the lockdown [Figure 3]. Among these, 24 (33.8%) patients could reach our hospital emergency. The remaining patients either went to a different hospital, took telephonic advise from a doctor or did not seek any medical care. There was a delay in seeking emergency services in five patients. The common causes of not seeking emergency care or a delay in seeking care included fear of contracting corona virus, transportation difficulties or distance from the hospital and concern that they would not be allowed in

the hospital as hospitals would only be catering to COVID patients [Figure 3].

Telemedicine

Four hundred seventy-four patients (65.1%) found telemedicine as an acceptable means to follow-up with their doctor and were satisfied with their experience. Among the various subcategories of neurological illnesses, patients with muscle and peripheral nerve disorders were least satisfied with teleconsultation. Patients with stroke and neuroimmunological illnesses were more likely to avail telemedicine services during the pandemic [Table 3].

DISCUSSION

Several studies have assessed physicians outlook of the lockdown, but scarcity of data exists about patients' perspective and concerns.^[4,5] Ever since the pandemic started, health care priority shifted towards management of COVID-19 patients and an unavoidable neglect of non- COVID illnesses. The present study assessed patient's concerns, problems encountered and drug compliance during the lockdown period.

Lockdown concerns

Almost 50% of the patients who participated in the study had health-related concerns. An apprehension regarding how to contact their treating physician or hospital if needed was the most common concern in our patients. Patients also feared either worsening of existing illness during the pandemic or getting infected with the novel corona virus. A similar assessment in diabetic patients reported a slightly higher percentage of people with such concerns.^[6] In our cohort, concerns regarding availability of drugs was seen in only 10% patients which was lower than what was observed in another study on relapsing remitting multiple sclerosis (MS) patients.^[7]

Table 2: Drug compliance and monitoring of diabetes and hypertension in the stroke cohort

	Diagnosis		Total
	Stroke: Ischemic (n)	Stroke: Hemorrhagic (n)	
Taking drugs			
Yes	108	15	123
No	4	0	4
Total	112	15	127
Did you check blood pressures			
Yes	62	10	72
No	12	5	17
Total	74	15	89
Did you check blood sugar			
Yes	20	3	23
No	4	0	4
Total	24	3	27

Table 3: Telemedicine experience of patients across the cohort

Category of neurological illness	Total cases (N=727)	Acceptability of telemedicine, n (%)
Stroke	128	95 (74.2%)
Neuroimmunology	75	56 (74.7%)
Muscle and neuromuscular junction	40	22 (55%)
Dementia	5	3 (60%)
Neuroinfection	32	21 (65.6%)
Peripheral neuropathy	25	13 (52%)
Epilepsy	232	140 (60.3%)
Ataxia	5	5 (100%)
Primary headache	58	38 (65.5%)
Vascular disorders	3	1 (33%)
Movement disorders	67	41 (61.2%)
Miscellaneous	57	40 (70.2%)

Drugs used in MS are not readily available to all patients and could have led to patients being worried.^[8] If patients depend on government agencies or hospitals for the disease modifying therapy, the lockdown has complicated the issue further.

Drug compliance

Most participants (~90%) in our study were able to procure their medications as medical stores were labeled essential service and remained functional during the lockdown.^[9] Only a small proportion of patients were not on any medication at the time of interview. Drug default was rare amongst our patients. Our neurology outpatient service runs several comprehensive subspecialty clinics for stroke, MS, neuroimmunology, epilepsy, movement disorders, and headache. In these clinics, patients are regularly educated and counselled about the nature of their disease; the importance of monitoring risk

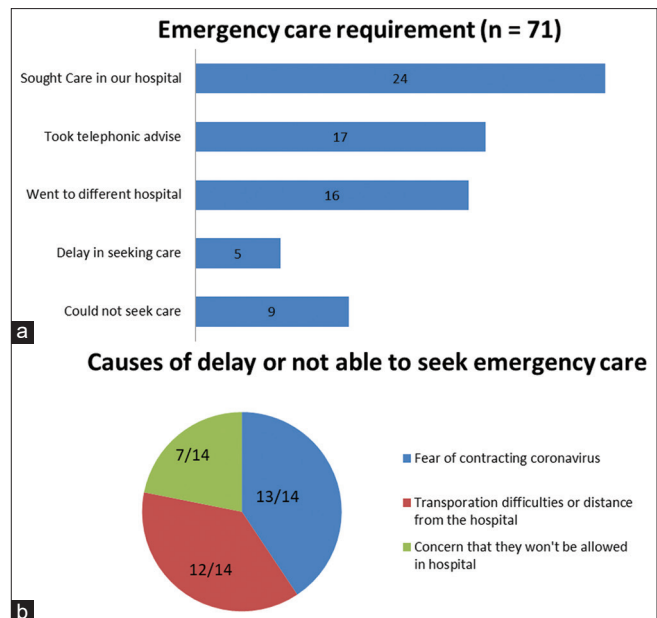


Figure 3: (a) shows the emergency care requirement among the study population, (b) depicts the causes of inability to seek emergency care factors particularly in stroke patients and also the need for taking medications regularly. This probably ensured the good compliance that we observed even during the lockdown. Studies have shown that good education sessions can improve drug adherence.^[10]

Majority of the stroke patients were taking their medications as prescribed. The feedback regarding monitoring of stroke risk factors such as type 2 diabetes mellitus, checking blood pressures regularly and avoiding addictions such as smoking, tobacco chewing and alcohol consumption were also encouraging. Stressful times during the pandemic have the potential of either causing increased use or relapse of substance abuse.^[11,12] However, during the lockdown, procuring alcohol or tobacco was not possible and that may have led to our patient's abstinence. However, on questioning we found that patients had deliberately made an effort and kept away from addictions.

Patients on immunosuppressants or immunomodulatory drugs or disease modifying therapy were also found to be quite compliant. Initially as the COVID-19 broke out, there was a theoretical possibility that patients on immunosuppressants or with autoimmune diseases could be at an increased risk of COVID-19 or of experiencing a more severe disease course in case of infection. However, as per the emerging data, it has become clear that immunosuppression possibly does not increase the propensity to have a severe disease or increase the likelihood of contracting infection.^[13,14] A retrospective study which analyzed the clinical characteristics of deceased patients found no association with immunosuppressant therapy.^[15] Guidelines for management of demyelinating diseases from India also endorse a similar sentiment and advise to continue immunosuppressants, immunomodulatory and disease modifying therapy.^[16]

Emergency care requirement and access to emergency services

Studies have shown that the number of cases of all specialties reporting to the emergency department has decreased. Range and colleagues have shown that the admissions for myocardial infarction in the French percutaneous coronary intervention centres dropped by 25%.^[17] Similar kind of findings were observed in a study conducted in the United States.^[18] In another study, authors observed a ~40% decline in the number of patients who underwent neuroimaging for evaluation of acute ischemic stroke during the pandemic.^[19]

From our cohort, 71 patients required emergency care or assistance from a physician. Common reasons patients cited for not accessing emergency services and delay in seeking care were fear of contagion, transportation difficulties and alternatively being able to seek telephonic advice from their doctor. The fear of contracting virus as a cause of not coming or delaying arrival to hospital during the time of need was also seen in other studies.^[7,18] Interestingly, the percentage of patients who required emergency care in our study was lesser than the reduction in emergency cases seen across other studies. This could be because participants in our study were able to maintain good compliance to drugs that they were already on. The study published by Siegler *et al.*^[20] observed that the number of new stroke patients (and not recurrent strokes) presenting to emergency had dropped by 40%.

Telemedicine experience

Two-thirds of our patients expressed satisfaction and accepted teleconsultation as an option for follow-up with their health care providers during the pandemic. In the past, studies have shown the potential utility of telemedicine in delivering health care.^[21,22] As hospitals try to limit overcrowding in outpatient clinics, telemedicine is being increasingly advocated across various subspecialties of neurology during the COVID-19 pandemic.^[23-25] Telemedicine is a suitable alternative to the brick and mortar visits to outpatient departments especially for those patients who have a stable disease course and seem to be doing well on therapy.

Limitations

Our study has few limitations. We relied on the patients' word regarding drug compliance and there was no way to confirm the veracity of their claim. Second, as our stroke patients were already on secondary prophylaxis the proportion of patients requiring emergency care was less. Also, the patients who were interviewed had already been contacted via telemedicine so they had some form of contact with the healthcare. This may not be an accurate representation of the number of people seeking emergency services for the first time and also does not capture the problems faced by patients coming to the hospital for the first time for their illness.

CONCLUSIONS

To conclude, the ongoing pandemic will continue to pose challenges to both physicians and patients. We will have to

find ways to ensure that non-COVID patients' care is not compromised. Patients in follow-up may need to be contacted regularly and counselled regarding the importance of remaining adherent to therapy during this stressful time. Governments must ensure that the hospitals and drug dispensing units are readily accessible to the patients with nonCOVID illnesses. Increasing the scope and practice of telemedicine can successfully reinforce care of chronic non-COVID diseases.

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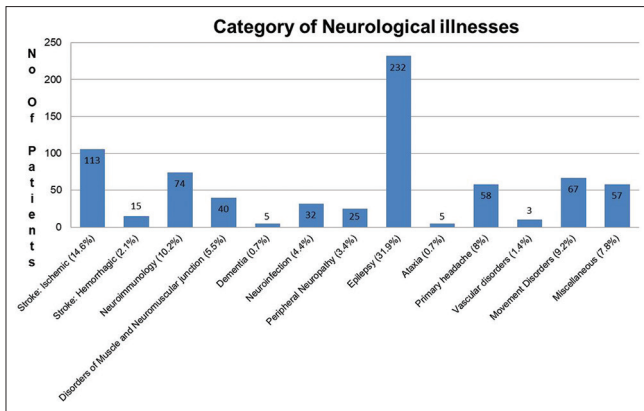
Conflicts of interest

There are no conflicts of interest.

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Supplementary Figure 1: Category of Neurological illnesses