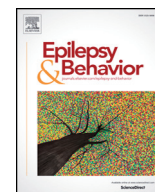




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COVID-19 containment and its unrestrained impact on epilepsy management in resource-limited areas of Pakistan

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ABSTRACT

The current pandemic of coronavirus disease 2019 (COVID-19) that led to an unprecedented crisis with significant health, social, and economic repercussions presented more serious concerns for those living with some chronic conditions such as epilepsy. This study was aimed to find out impact of the COVID-19 pandemic on management of epilepsy. A cross-sectional study was conducted through telephone interviews, targeting 213 caregivers of pediatric patients with epilepsy, belonging to underserved areas of Faisalabad, Punjab, Pakistan. A simple questionnaire was designed to record the responses of participants relevant to the direct and indirect effects of COVID-19 pandemic and their knowledge about possible ways that can be accessed for the management of epilepsy during an ongoing pandemic. The current study, which holds 77% of the respondents from rural areas and 23% from urban settings, showed that partial measures of lockdown taken to stop or slow the spread of COVID-19 resulted in adverse economic and health outcomes in the said population including cancelation of follow-up visits, worsening of seizures, job loss, burden of antiepileptic drugs (AEDs) costs, and discontinuation of medicines. Furthermore, knowledge about alternative ways to access health facilities was found very poor among caregivers. Income sources of poor people disrupted by lockdown can lead to unintentional nonadherence to medication, which is a clear picture of inequitable distribution of resources. This study highlights the major issues faced by the caregivers during this ongoing pandemic of COVID-19.

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1. Introduction

Epidemics are always a great menace to global health security. The current pandemic of coronavirus disease 2019 (COVID-19) affected all countries around the globe and has changed the entire world within a few months. Social isolation is advised throughout the world to prevent the potential transmission of infection. This public health emergency of international concern (PHEIC) delineates unprecedented crises with significant health, social, and economic repercussions [1]. The medical community is facing many challenges of practical and ethical nature requiring rapid response [2]. Lockdown, self-isolation, and social distancing are some of the measures taken by governments of different countries aimed at decelerating the COVID-19 spread. The COVID-19 pandemic influenced everyone around the globe, but it can cause

more concerns for people living with chronic illnesses including neurological disorders like epilepsy [1].

A strict lockdown can affect these patients adversely as they require regular follow-up visits and prescription refills. On the other hand, control of COVID-19 pandemic demands discontinuance of all routes of probable transmission [3]. Increased probability of being infected by outpatient department visits compelled the patients and their caregivers into postponement of appointments leading to further health consequences [2]. With more than 65 million people affected worldwide, epilepsy is the fourth most commonly occurring neurological disorder. The estimated prevalence of epilepsy in Pakistan is 9.99 per 1000 population with the highest prevalence in people living in rural areas [4]. Importantly, epilepsy cases are not uniformly distributed; instead, a large number of patients belong to resource-poor regions [5,6], places that are more at risk of epidemic outbreaks, thus making epilepsy management more difficult during an epidemic. Resource-poor countries are incapable to take on the enormous medical, economic, and social challenges caused by epilepsy. Compromised healthcare systems in these countries are unable to provide cost-effective care because of widespread poverty and illiteracy, due to

Abbreviations: GEFS+, generalized epilepsy with febrile seizures plus; CAE, childhood absence epilepsy; JME, juvenile myoclonic epilepsy; DEEs, developmental and epileptic encephalopathies; IGEs, idiopathic generalized epilepsies.

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which a great proportion of these patients remain undiagnosed and untreated, causing the treatment gap and maximizing the overall burden of epilepsy [7].

The health system challenges in developing countries are somewhat different from developed countries [8]. For a low–middle-income country like Pakistan, spending less than 1% of gross domestic product (GDP) on health, the management of chronic disorders like epilepsy is a great challenge during this pandemic [9].

Like all other chronic disorders, epilepsy management demands regular medical checkup and sustainable supply of antiepileptic drugs (AEDs) [6]. However, in the current pandemic situation, community containment is inevitable, which in turn restricts the medical interaction between neurologists and people with epilepsy (PWE), ultimately making epilepsy management tougher than ever [10]. Presently, there is a lot of precariousness and queries concerning epilepsy and COVID-19. It has been proposed by researchers that the risk of acquiring COVID-19 infection for people affected with epilepsy and the general population is the same [11]. However, the paucity of AEDs, the presence of comorbidities, and lack of medical assistance during the pandemic situation make PWE (even if seizures are controlled) more prone to COVID-19 infection as compared with the healthy population [12,13].

Although current AEDs can effectually control seizures, still, one-third of the affected people continue to experience seizures because of drug-resistant epilepsy. Therefore, regular visits of outpatient clinics are indispensable for the optimization of antiseizure therapy and better management of behavioral and psychological problems related to epilepsy [14].

The present study was aimed to find out the impact of COVID-19 containment measures on the management strategy of low literate caregivers of patients living in resource-limited areas of Pakistan, one of the active hotspots of the pandemic.

2. Methods

2.1. Study design

A cross-sectional study was designed to collect data from caregivers of patients with different epilepsy conditions (Fig. 1). It was conducted between July 13 and July 24, 2020, ~115 days after partial lockdown was implemented in Pakistan. The study was approved by the Bioethics Committee of the University of the Punjab, Lahore, Pakistan.

2.2. Participants' background

Participants of this study were the caregivers of pediatric patients with active epilepsy, recruited for another study under higher education commission (HEC)-funded project before the COVID-19 pandemic. All patients belonged to different areas of division Faisalabad, Punjab, Pakistan. Most of the participants were from rural settings and illiterate or low-literate (assessed through already present data), so the online survey was not an option to record responses, while in-person interviews were discouraged because of the current dreadful pandemic.

2.3. Questionnaire design

A simple self-administered questionnaire holding most of the dichotomous questions was designed after the consensus of all the authors. Urdu being a national and frequently used language in Pakistan was selected to record responses. Initially, a 16-item questionnaire was designed and tested through a pilot study to check the feasibility of comprehension for respondents. All questions relevant to COVID-19 testing in patients and close contacts, symptoms, and standard operating procedures (SOPs) were excluded from the questionnaire after

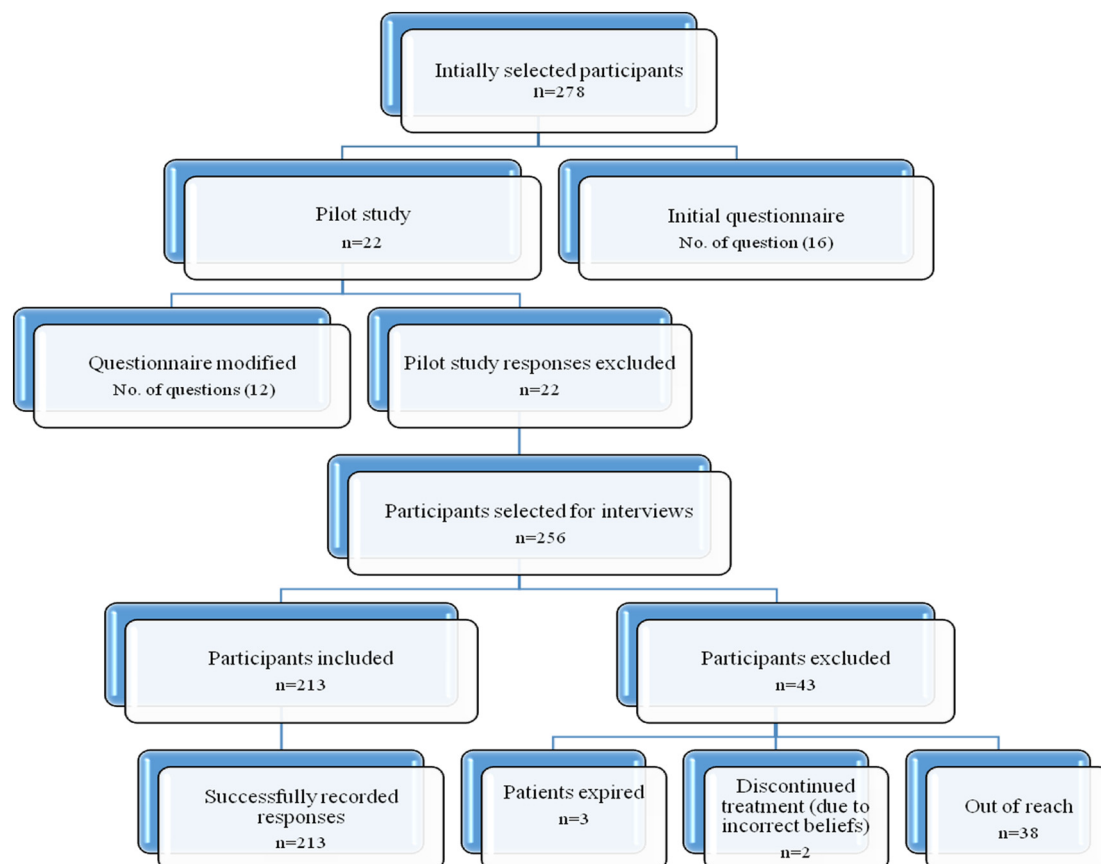


Fig. 1. Cross-sectional study design.

Table 1
Responses of the caregivers.

Survey questions	n (%)
Gender	
Female	128 (60.1)
Male	85 (39.9)
The age group of the pediatric patients	
1–5	87 (40.8)
6–10	83 (39.0)
11–15	39 (18.3)
16–20	4 (1.9)
Area	
Urban	49 (23)
Rural	164 (77)
Cancellation of appointment due to COVID-19 pandemic	
Yes	137 (64.3)
No	76 (35.7)
Medication discontinued due to disrupted income sources	
Yes	37 (17.4)
No	176 (82.6)
Reliance on free AED supply from hospital	
Totally	65 (30.5)
Partially	122 (57.3)
Unsure	26 (12.2)
Worsening of seizure during the current pandemic	
Yes	57 (26.8)
No	156 (73.2)
Job lost due to COVID-19 pandemic	
Yes	81 (38)
No	132 (62)
AED cost burden aggravated in lockdown	
Yes	145 (68.1)
No	68 (31.9)
Do you have a smartphone?	
Yes	86 (40.4)
No	127 (59.6)
Do you know about telemedicine?	
Yes	16 (7.5)
No	197 (92.5)

AEDs: antiepileptic drugs.

analyzing the reluctance in response due to prevailed COVID-19 chaos in low-literate communities. A total of 12 questions containing the questionnaire were finalized to record responses.

2.4. Telephone interview

A telephone interview was conducted to record the responses of all caregivers. Although it has some limitations, it can be an efficient method of data collection [15]. All pertinent information like purpose, benefit, and procedures involved in the study were provided to the subjects and given ample opportunity to ask any question regarding data usability. After answering the respondents questions (if they had any) and explaining that all the data collected from patients will be used anonymously and at no stage in the study, their identity will be revealed, a formal verbal consent was obtained by asking “Do I have your permission to ask you questions relevant to your child’s disease and its management and use this protected health information for research purpose?”. After getting a “yes” answer from each caregiver recruited in this study, interview was conducted. Three of the caregivers reported unexpected death of their child even though the seizures were under good control, seemingly a sudden unexpected death in epilepsy (SUDEP) (not confirmed by postmortem), while antiseizure treatment was discontinued by 2 patients, reporting that epileptic seizures of their children have some supernatural explanation and thus, were excluded from the study. Thirty-eight contact numbers could not be reached to record the response.

3. Results

After explaining every question to the respondents, a total of 213 responses were recorded successfully (Table 1). Gender-wise prevalence of epilepsy in different age groups (Fig. 2), education level of caregivers (Fig. 3), and particular type of epilepsy (Fig. 4) were also analyzed.

4. Discussion

The horrific COVID-19 pandemic posed numerous challenges to healthcare systems and economies worldwide. It has forced healthcare professionals and policy makers to shift their prime focus towards patients infected with COVID-19 by dedicating major health facilities

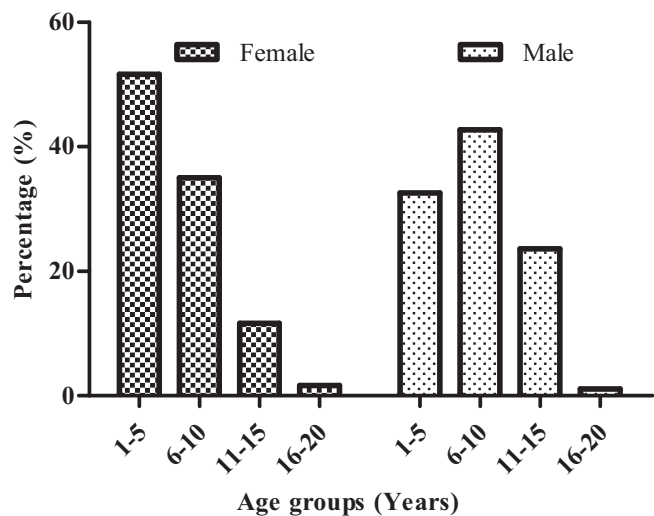


Fig. 2. Gender-wise distribution of patients among different age groups. The highest prevalence was observed in 1–5 and 6–10 years age group in females and males, respectively.

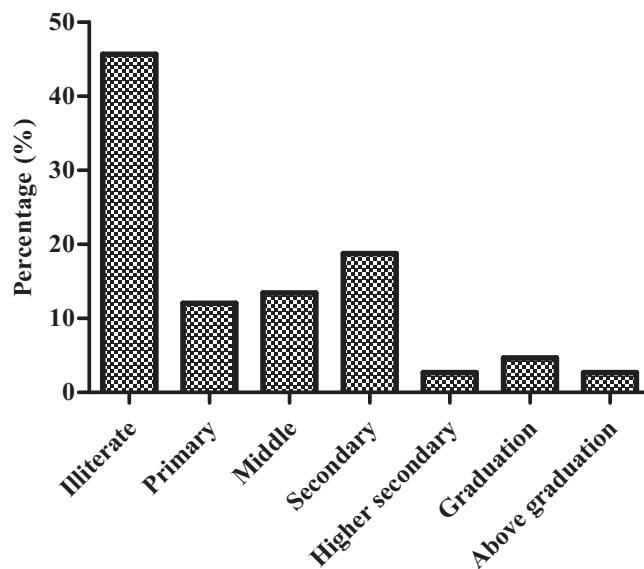


Fig. 3. Education level of the caregivers. Majority of the caregivers were illiterate. Only a small fraction of the caregivers were well educated.

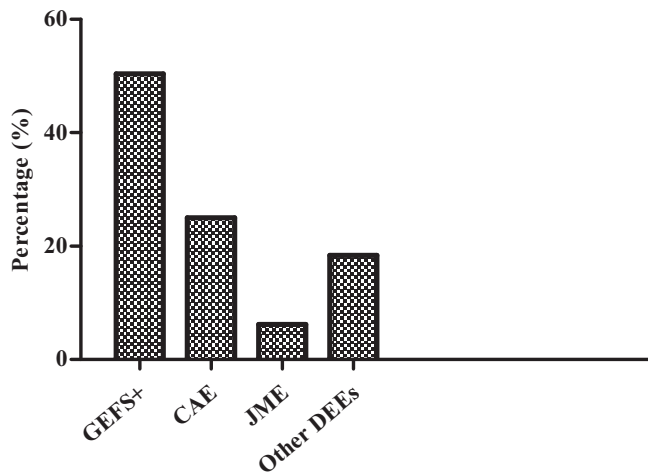


Fig. 4. Prevalence of epilepsy of a particular type among pediatric patients of the current study. The highest prevalence of GEFS+ was observed, while JME prevalence was lowest among all IGEs.

to them [16]. Pakistan was among the countries facing a substantial spike in COVID-19 cases due to loosened restrictive measures.

Face-to-face appointments have been canceled all over the world either by patients or by clinicians forcefully to protect the patients and healthcare professionals from being infected [17]. It is no different from Pakistan where because of the lockdown, majority of people canceled or postponed their neurology visits due to nonavailability of transport and fear of being infected after visiting hospitals. It is evident from the current study that majority of the respondents postponed their follow-up visits. A greater number of patients in this study belonged to rural areas following the fact of its prevalence [4]. Aledo et al. reported seizure worsening in some cases during lockdown as presented in our study [18]. The pathophysiology of seizures exacerbation is not completely understood; however, selection of inappropriate AED can also aggravate the condition [19], which urgently requires the medical consultation that is tough during the current situation.

Uncontrolled seizures can affect the immune system by causing malnutrition; moreover, the mortality rate linked to epilepsy is high among those with uncontrolled seizure conditions [20–22]. In the current study, trend of medicine discontinuation was observed due to nonaffordability despite the fact that discontinuation of AEDs without prior consultation with the neurologist can result in serious medical consequences [23]. Rural populations face innumerable constraints including weaker financial status and having out-of-pocket expenses in epilepsy treatment [24]. The lower socioeconomic status (SES) of the patients makes them susceptible to medication nonadherence, but it can be inflamed especially during the current pandemic because of losing jobs and wages associated with a disruption in the source, which makes the provision of drugs accessible as noticed in the present study [25]. Nonadherent patients with epilepsy conditions are at greater risk of complications emanating from uncontrolled seizures. The current study holds majority of the respondents from rural settings who largely rely on the partial supply of free of cost AEDs from government hospitals, which was disrupted because of lockdown, making the cost of treatment unbearable.

Services regarding healthcare are disrupted worldwide because of the measures taken in the wake of an ongoing pandemic. It has led to the conversion of onsite visits into telemedicine visits [26], which can be proven significantly effective in supporting remote delivery of services to patients with chronic conditions including epilepsy [10]. Keeping in view the benefits of telemedicine, the Punjab government's information technology (IT) sector had launched a major project in Pakistan that connects 250 rural basic health units to urban centers through video-link, where doctors provide consultation [27]. People

belonging to urban areas have access to nearby hospitals, while there are many constraints for rural communities including geographic distance and traveling cost. Telehealth in Pakistan is comparatively better than it was in previous years, but it still needs more cogitation particularly in underserved and rural areas where it is poorly integrated [28].

Because of the current pandemic, various hospitals in Pakistan have started telehealth for COVID-19 and other ailments rapidly through various platforms including social media (WhatsApp) to ensure the regular provision of healthcare services [29]. The use of advanced technology like smartphone applications can greatly facilitate the communication between patients/caregivers and physicians. Patients can also share videos of seizure events with the caring physician for better diagnosis and treatment, ultimately implementing telehealth at a larger scale [30]. However, it is only possible when the patients have access to smartphones with enough knowledge about its operation. The current study showed that the majority of the caregivers were illiterate (Fig. 3). Many of them do not have smartphones, and more than 90% do not know about telehealth/telemedicine. Very few caregivers belonging to urban settings were aware about telemedicine. Awareness about telehealth services and all the ways to access it is requisite. The role of nongovernmental organizations (NGOs) cannot be negated in sustained awareness activities and reducing the epilepsy treatment gap (ETG) through direct and indirect measures of public awareness. In 2001, the Comprehensive Epilepsy Control Programme of Pakistan (CECP) was initiated under NGO to combat the various challenges and paucities in knowledge, attitude, and practice (KAP) about epilepsy, especially stigma and ETG. The CECP has two major components named as Epilepsy Support Pakistan (CECP-ESP) and National Epilepsy Centre (CECP-NEC), for awareness, mass education, integrated management of PWE, professional education, and the basic research [31]. Nongovernmental organizations should come forward during these unwelcoming situations of COVID-19 pandemic to spread awareness especially in underdeveloped areas to counter the present health challenges.

The World Health Organization (WHO) urges Pakistan to implement intermittent lockdown to control the spike in new cases. Extension of lockdown can promote medication nonadherence among those people who reported the cost of treatment a great burden in the absence of wages. No one knows when this dreadful pandemic will end, so if the government uplifts the restrictive measure to give relief, still fear of this pandemic will probably exist among people and refrain from visiting clinics.

5. Conclusion

Our cross-sectional study is one of the first reports from Pakistan that provides information about the direct and indirect effects of the pandemic on a vulnerable population. The majority of the caregivers are finding it difficult to continue the same management of the disorder as before the pandemic leading to serious outcomes like seizures exacerbation. Lack of awareness hinders the adoption of telemedicine especially in rural areas making the management of epilepsy tough for these people.

Recommendations

Policies to counter challenges in the management of chronic disorders during the COVID-19 pandemic must address the people of resource-limited areas, and they should be provided with free AEDs at doorstep at least during such uninviting situations, making their fight against this disorder easy. Awareness campaigns through government and NGOs should be started at the grassroots level to make people well aware of their disease and all possible ways that can be accessed for the management of it during such inevitable situations. To combat the present challenges posed by an ongoing pandemic, communication through telehealth services and uninterrupted supply of medicines by all means is demanded. Unfortunate though inevitable, the COVID-19 pandemic exposed the inadequacies of the present healthcare systems.

Now this pandemic should be exploited to setup better infrastructure including implementation of telehealth to deal with current and future inevitable epidemics.

Data availability

All the relevant data are present in the article.

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Declaration of competing interest

The authors declare that there is no conflict of interest regarding the publication of this paper.

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