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# Experience during COVID-19 lockdown and self-managing strategies among caregivers of children with epilepsy: A study from low middle income country

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ABSTRACT

*Purpose:* Abrupt halt of service provision due to pandemic state of COVID-19, significantly affected care of patients with chronic diseases like epilepsy; its impact being greater on caregivers of vulnerable groups such as children with epilepsy. We performed this study to describe difficulties posed by the lockdown to caregivers of children with epilepsy in a low-middle income country and describe their responses and self-management strategies to overcome difficulties and prepare for a recurrence.

*Method:* A cross-sectional all-island survey was carried out at paediatric neurology centers in Sri Lanka. Data was gathered via a face-to-face interview after the lockdown period. Parental stress level was evaluated using a self-rating Stress Assessment Questionnaire.

*Results:* Caregivers of 140 children with epilepsy from seven centers served by paediatric neurologists were interviewed. Mean duration of epilepsy was 7.9 years(SD 4). Majority were on one (52.1 %) or two (20 %) anti-seizure medications regularly. The pandemic did not affect epilepsy control in majority (87.3 %), however, signficant proportion faced difficulties over regular reviews and presecription refills. Despite difficulties, 87.1 % of parents maintained dispensing anti-seizure medications to their child regularly. Caregivers demonstrated healthy self-management strategies such as awareness on medications and access methods to healthcare during lockdown and remained confident of accessability to services. Stress was experienced in < 5%.

*Conclusion:* Lockdown status for COVID-19 did not significantly affect the control of epilepsy in children though it posed difficulties for regular reviews and obtaining medications. Self-management strategies will help caregivers to adopt to new-normal status and potential future outbreaks.

## 1. Introduction

Emergence of coronavirus disease (COVID-19) since its first identification in December 2019, created a massive global health emergency. A pandemic state was declared by the WHO on 11th of March 2020. Unprecedented spread of disease calling for disaster management strategies, resulted in an unexpected stand still of many regular healthcare functions.

Epilepsy is the commonest chronic neurological disorder. Daily medication to prevent recurrence and regular review to assess seizure control and compliance are vital for good disease control. Abrupt discontinuation of medications increases risk of triggering seizures [1]

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and developing status epilepticus [2].

Having a child with special needs during pandemic is shown to be associated with increased rates of depression and increased strain among caregivers [3]. Reports on epilepsy caregivers' perspectives during COVID-19 are few. Inability to reach neurologist using telemedicine resources, living in homes without a terrace or yard, economic problems, loss of regular stimulation and physical therapies, cancelation of essential medical appointments and difficulties finding their antiseizure medication at a pharmacy were described in a Spanish study as the obstacles faced during lockdown [4]. They also described new onset symptoms of anxiety or depression in the caregivers and tendency to avoid seeking medical advice due to fear of COVID-19 infection. Study from a Pakistan, described cancellation of appointments (64 %), discontinuation of medication (17 %), increase of seizures (27 %), non-accessibility to a smart phone (40 %) as difficulties encountered by patients with epilepsy [5]. In a study from India related to children with infantile spasms, difficulties in making clinical judgement were experienced by health care professionals during COVID-19, while caregivers had problems related to seeking medications (ACTH, Vigabatrin etc.). These difficulties were confounded by the heterogenicity of resource allocation in the urban and rural communities [6].

Sri Lanka is a middle low-income country with a population density of 24 million served by a free health care system. The incidence of childhood epilepsy is 5.7 per 1000 children between ages of 0–16 [7]. First case of COVID-19 within Sri Lanka was identified on 1st of March 2020. All island curfew and lockdown status were imposed by third week of March for the next six weeks. Regular access to hospitals was abruptly halted causing dramatic challenges in maintaining emergency care, regular follow ups and prescription refills. Initiatives from the state health service such as telephone consultations, hotline help, supply of medications via mail attempted to ease some of these difficulties.

This study was conducted to describe the difficulties faced by caregivers of children with epilepsy from a low middle income country, Sri Lanka, assess caregivers' stress and to describe self-management strategies and future preparedness in the caregivers.

## 2. Method

A multi-centre cross-sectional study was conducted after re-establishement of normal health care services in Sri Lanka following the successful control of the first outbreak of COVID-19. The study was conducted at seven out of the eight public centres in the country served by paeditric neurologists, facilitaing an island wide assessment of status covering both urban and rural care facilities. This included two university units. Caregivers registered in the state health sector and dependent soley on free healthcare service for regular supplies and reviews were included.

Caregivers of children with epilepsy aged six months to 16 years were randomly selected when they returned for regular clinic follow up. An epilepsy diagnosis of less than 6 months or those not requiring frequent reviews (at least 3 monthly), were excluded. Care-givers' perceptions were assessed by a self administered questionnaire based on items listed in similar caregiver assays during COVID-19. Care-givers' stress level was assessed using a translated version of Caregiver self assessemnt questionnaire, an 18-item self rated questionnaire developed by the American Medical Association [8]. Self-management strategies were also evaluted. Data were analyzed using Statistical Package for Software Sciences (SPSS version 22). Frequency distributions were used to summarize categorical data. Summary measures were described with means, 95 % confidence intervals and associations were described using the Chi-Square test. This study was approved by the Ethics review Committee of the Faculty of Medicine, Colombo (ERC/20/117).

## 3. Results

A total of 140 parents of children with epilepsy out of 150 were interviewed (93 % response rate). The primary caregiver interviewed was the biological parents in 98.6 %; most often the mother (93 %). The demographic details of the parents are given in Table 1.

The mean age of children with epilepsy was 7.87 years (SD 4.0); mean duration of epilepsy was 4.43 years (SD 3.37). The number of anti-seizure medications regularly used was one in 52.1 %, two in 20 % three in 10 % and more than three in 17.9 %. Type of epilepsies in our population are summarized in Table 2.

Their child's epilepsy control during the lockdown period, remained stable without change in fequency of seizures in 59.3 %. Twenty eight percent indicated better control than at other times while only 12.1 % reported an increased frequency. Thirteen percent experienced seizures requiring at least one admission to hosptial during the COVID-19 lockdown. Only few (5 %) experienced seizures lasting more than five minutes.

Regarding review and prescription refill, 79.3 % indicated that they were not able or did not come to the regular clinic; reasons being clinics not functioning as usual for 39.6 %, difficulties in transport for 61.3 % and 36 % opting to manage with medications already available with them due to fear of COVID-19. However, 87.1 % of caregivers confirmed having an access to regular supply of medicine through public or private means.

With regard to parental experience during COVID-19, difficulties experienced included not recieving medications in the post (48.6 %), inability to afford purchase of medications (57.1 %), inability to reach a pharmacy due to restrictions on mobilisation (60 %) and halted transport services (77.1 %). Majoriy (72.9 %) indicated that they could not manage the child's condition with confidence during this period.

Problems experienced by those who came to hospital included transport difficulties in 86.4 %, delay in admission in 45.5 %, slow attitude by staff in 18.2 % inability for the family members to visit them in 22.7 %, shortage of drug supplies within the hospital 22.7 % and refusal of admission in 4.5 %.

Based on the experience during COVID-19, the caregivers indicated readiness for a similar lockdown by being aware of the name of child's epilepsy medication (88.6 %), knowing the doses (84.3 %), having adequate supply of medications (72.5 %), maintaining one month of extra supplies by 70.7 %, feeling confident of having access to medications in 82.9 %, being aware of how to contact their child's doctor in 87.1 % and feeling confident about having help made availabe in 90.7

**Table 1**
Demographic data of the population.

| | Frequency | Percentage |
|---|---|---|
| Age of Caregiver | | |
| 20–30 | 14 | 10 |
| 30–40 | 83 | 59.3 |
| 40–50 | 35 | 25 |
| 50–60 | 5 | 3.6 |
| >60 | 3 | 2.1 |
| Race | | |
| Sinhala | 120 | 85.7 |
| Tamil | 11 | 7.9 |
| Muslim | 8 | 5.7 |
| Bouguer | 1 | .7 |
| Place of Residence | | |
| Urban | 80 | 57.1 |
| Rural | 60 | 42.9 |
| Monthly income (Sri Lankan Rupees)* | | |
| >20,000 | 52 | 37.1 |
| 20000–50000 | 70 | 50 |
| 50000–100000 | 14 | 10 |
| >100,000 | 4 | 2.9 |
| Highest level of education | | |
| Primary | 53 | 37.9 |
| Secondary | 80 | 57.1 |
| Technical | 1 | .7 |
| Graduate | 6 | 4.3 |

* USD = 190 SLR.

**Table 2**
Types of epilepsies.

| Type of epilepsy | Frequency | Percent |
|---|---|---|
| Absence epilepsy | 5 | 3.57 |
| Centro-temporal spike disease | 11 | 7.85 |
| Developmental epileptic encephalopathy | 7 | 5 |
| Lesional Focal epilepsies | 57 | 40.7 |
| Genetic Generalized Epilepsy with Generalized tonic clonic convulsions | 33 | 23.57 |
| West Syndrome | 5 | 3.57 |
| Myoclonic epilepsy | 3 | 2.14 |
| Combined focal and generalized epilepsy | 9 | 6.42 |
| Undifferenciated | 10 | 7.14 |
| Total | 140 | 100.0 |

%. Stress assessment using the Caregiver self assessement questionnaire identified that only 4.3 % of caregivers experienced stress that warrented review by a practitioner. There was no significant relationship between level of stress with economical strata (p = .781), level of education (p = .144). However, caregivers from rural backgrounds were more stressed than the caregivers from urban backgrounds. (p = .041) Only 2.1 % had accessed help through internet to resolve their concerns related to the epilepsy in their child.

## 4. Discussion

This study among caregivers of children with epilepsy, totally dependent on free health care from a LMIC country identified problems they faced during the lockdown. Epilepsy control and emergencies suffered less in comparison to the difficulties and limitations experienced by caregivers for maintaining daily prescription. Caregivers' ability to cope to the situation was healthy and their preparedness for recurrence in the future was positive in most aspects. These findings would be helpful to optimize care support to patients and caregivers during the current second wave of infection experienced in the country.

It is known that parents with additional caregiving responsibilities, experience potent negative responses to disasters more acutely [9]. This increased perceived child stress is positively associated with child-parent relationship conflict and negatively associated with child-parent closeness [9]. A community survey from University of Pittsburgh showed that family caregivers report an increased responsibility during the COVID-19, related to interrupted access to care, resulting in lifestyle adjustments, increased worry, fear, depression and anxiety [10].

Specific care guidelines for both clinicians and caregivers for different conditions, are useful for optimizing patient care in a pandemic situation [11]. Guidelines from epilepsy, neurology and paediatric professional organizations have been published to help clinicians [12] however, support for caregivers of epilepsy particularly for those beyond the English-speaking borders have been left to local resources [13]. Means for access to information is mainly web-based and relies on accessibility to internet and or smart phone. Those poor, less educated and without access to internet tend to suffer most [5]. The majority of parents (95 %) in our study group did not reach a college or technical level of education. Their ability and intuition to access information online is likely to be low and likelihood of understanding information in a foreign language is even less likely.

In response to restrictions imposed due to COVID-19, health care professional had to seek differential options for care for different chronically ill patients [14,15]. In care of children with epilepsy, the main issues faced were related to delivery of regular treatment plans more than addressing emergencies, similar to that described in our study. These included inabilities to attend clinics or routine electroencephalography evaluations, difficulties in management intensifications i.e. in infantile spams, restrictions on starting new therapies such as ketogenic diet or limitation of epilepsy surgeries [16,17]. Contrary to our finding of only 12 % experiencing an increase of seizures, two studies described 29–33 % of patients as experiencing more seizures [18,19]. Both these studies were in adults with epilepsy and with long duration of epilepsy as in the latter. Both these factors may explain the higher proportion with increased seizures.

Telehealth consultation as feasible option with evidence of effectiveness in providing medical advice is described [20], particularly in chronic neurological disorders [21] from both high and low resource settings [22,23]. However, we do not know the usefulness of this service to all as those without telephone would have been excluded. Further, the effectiveness of telehealth consultation would vary depending on the services available in the technology used and the caregivers ability to use options available. A decision making tree was proposed by Kuroda Naoto to improve the limitations posed for decision making using telemedicine for epilepsy [24]. However, in low income settings, these consultations often are limited to a telephone call having no video consulting or prescription facilities, thus limiting the services that can be offered via telehealth. Even in an advanced setting like Spain, a survey among neurologists revealed that 88 % of teleconsultations were done only through telephone calls [25].

Sri Lanka in spite of its low ranking in global financial status, is ranked 71 out of 189 in the Human Development Index [26]. It has a strong preventive and a curative healthcare service, offered totally free to its citizens. It managed to control the COVID-19 pandemic during March to May 2020 successfully limiting the positive cases to 3374 patients, fatality rate to 0.22 % and zero community spread to no identifiable local case from June to September this year [27]. This was achieved at the expense of an island-wide curfew and lockdown for over 6 weeks. Although, the authorities launched special propaganda with emergency contact hotlines, adverts on state and social media outlining access to health services, our study findings speak of the difficulties faced by patients and caregivers as a result of these drastic measures enforced for COVID-19 prevention.

The present study performed immediately after return to normalcy for access to health care captured the recollection of the difficulties faced by caregivers during this period. The face-face interview which allowed free expression of their difficulties was a strength in this study. Expressions on lessons learnt and caregivers' readiness to face a recurrence were useful indicators of self-management strategies. Limitations in this study included its pure quantitative nature, lack of detailed difficulty assessments and non-assessment of caregivers' affective symptoms and quality of life. Assessment of coping may also have helped to describe a person's response to stressful or difficult circumstance better. In spite of these shortcoming, it identified that improving on prescription supply services, introducing more opportunity for teleconsultations, maintaining access to contact with key care physician as key aspects needing urgent attention particularly now when the country is experiencing a second wave since beginning of October. The low incidence of stress possibly indicated parental coping abilities and highlights importance of emphasis on self-management strategies such as knowledge on epilepsy, medication management, and problem-solving suggestions and psychosocial support during face-face or teleconsultations [13]. These stress responses may deteriorate with subsequent waves of COVID-19, hence, empowerment and support to caregivers should become an integral component of teleconsultations. Improving caregivers' knowledge on disease related emergencies and establishment of patient help hotlines, may help reduce admission during a pandemic.

## 5. Conclusion

The COVID-19 pandemic has resulted in significant impact on persons with epilepsy across the globe. Similar to most studies from both high and low income settings, maintaining drug supplies, visiting the physician, obtaining reviews posed greater difficulties to caregivers and patients with epilepsy, than by difficulties caused by the disease itself. The caregivers had adopted self-management strategies, which may have resulted in the low record of stress related to caring for their child with epilepsy during a pandemic situation.

## Disclosures

We would like to declare that any part of this study was not sponsored by financial group. None of the authors have any conflicts of interest to declare pertaining to this study. We confirm that we have read the journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

## Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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