Received: 15 June 2022 | Accepted: 16 August 2022

DOI: 10.1002/epi4.12646

Epilepsia Open® Open Access

ORIGINAL ARTICLE

Challenges for low middle-income people with epilepsy during the COVID-19 pandemic: *Lessons learnt, call for action*

Urvashi Shah | **Shivani Rajeshree** | **Parthvi Ravat** | **Mayuri Kalika** | **Saloni Mehta** | **Antara Sapre** | **Sangeeta H. Ravat**

Department of Neurology, Seth GSMC and KEM Hospital, Mumbai, India

Correspondence
Shivani Rajeshree, Department of Neurology, Seth GSMC and KEM Hospital, Mumbai, India.
Email: shivanirajeshree@gmail.com

Abstract

Objective: The COVID-19 pandemic impacted the care of people with epilepsy (PWE). Several online surveys were conducted but there is limited data regarding the impact on low-income PWE from lower-middle income countries (LMICs) who have no access or ability to answer online surveys. The purpose of this interview was to understand the challenges faced by low-income PWE during the lockdown phase of the pandemic.

Method: PWE visiting the epilepsy specialty outpatient department of a tertiary referral government hospital to avail of subsidized services were interviewed. In the interview, they discussed challenges in obtaining medical care, the impact on wellbeing, employment, and vaccination status during the lockdown phase of the pandemic.

Results: Out of the 214 PWE interviewed, 20.6% had increased seizure frequency, 28.9% did not have access to medication mainly due to travel restrictions, 30.5% reported lack of availability of medication and 50% were not able to afford the medication mainly due to loss of income. 51% were unable to have follow-up consultations. 36% reported worsening of mood and some reported impact on other aspects of wellbeing. The impact on wellbeing was significantly associated with an increase in seizure frequency ($P < .05$). The study revealed hesitation related to vaccines in the majority and expectations of financial support by the government and assistance for procuring medication. There was a lack of awareness about telemedicine services and the same was not adequately offered by government hospitals.

Significance: The study underscores the need to learn lessons from the challenging experiences of low-income PWE and create an action plan for the future to address the issues of lack of affordability of medical care and access to telemedicine. It is critical that the care of the marginalized, underrepresented PWE from lower-middle income countries is not neglected during a pandemic.

KEYWORDS

affordability of medical care, antiseizure medications, lockdown, telemedicine, wellbeing

1 | INTRODUCTION

The COVID-19 pandemic led to significant challenges for healthcare across the globe. Access to medical care and support for people with chronic neurological conditions like epilepsy was significantly impacted due to the lockdowns and restrictions imposed by several nations.[1] The International League Against Epilepsy (ILAE) COVID-19 and Telemedicine Task Forces conducted a global survey to understand how the care of people with epilepsy (PWE) was impacted during the pandemic.[2] The survey results described the changes in seizure frequency, challenges with obtaining medications, and significant impact on mental health. Additionally, the results highlighted the importance of telemedicine as a useful tool for providing health care for PWE during the pandemic. The special report emphasized establishing models of support to "prevent a parallel pandemic of unmet health care needs".

In India, a complete nationwide lockdown was imposed overnight on 24th March 2020 which lasted until 30th June 2020. The unlocking began in a phased manner with gradual lifting of restrictions in different parts of the country. In the state of Maharashtra, which was one of the worst affected states, stringent rules and regulations were enforced on the use of public transport. Local trains in the city of Mumbai are considered the lifeline of the city since they are the cheapest and most convenient mode of transportation. They were unavailable for the public till August 2021.[3] This made it very difficult for the common person to commute and seek health services in the hospital.[2]

Prior to the pandemic, patients belonging to the lower socio-economic class, from the city, outskirts, rural areas, and neighboring states used public transport to visit the tertiary referral government hospitals in the city to access subsidized medical care. The abrupt shutdown of transport services and forced isolation during the pandemic affected the socioeconomically vulnerable group significantly. The migrant population, who resided in the cities for work, had to return to their remote villages and face challenges of loss of employment, income, and access to healthcare services[3,5].

During the pandemic, various studies on PWE examined the impact on seizure frequency,[6,7] mood[8–11] and the challenges with accessing medications.[4]

However, all the surveys were conducted online and did not capture the experiences of the low-income group of patients who lacked the sophistication to access technology and respond to online surveys. The ILAE report[2] observed that a limitation of their survey was that the questionnaire was not available in many languages. Furthermore, it could be answered only by participants with Internet access, thereby marginalizing many PWE from major regions of the world.[12] It did not discuss the challenges faced by low income PWE. Hence, the current study was designed to understand the impact of the pandemic on the lives of this subgroup of PWE who could not answer online surveys. In order to ensure that the experiences of this group were adequately represented, one-on-one, in person, structured interviews were planned.

Key points

- Low-income people with epilepsy face significant challenges of accessibility, availability, affordability of ASMs during the pandemic.
- Increase of seizure frequency was significantly associated with worsening of wellbeing.
- There was a lack of awareness and availability of telemedicine services for the low-income group.
- An action plan for the future of people with epilepsy in lower-middle income countries needs to be formulated.

Although the peak of the pandemic appears to have passed, many countries are still struggling with minor waves[4–6] and certain countries are facing a resurgence of the infection and are imposing stringent lockdowns.[7–10] Hence, the data from this kind of study are important as these provides all stakeholders—doctors, hospitals, government agencies, and international organizations involved in the care of epilepsy, an understanding of the challenging aspects of a lockdown for the most vulnerable group of PWE. The purpose of this study is to provide pointers for Lower Middle-Income Countries (LMICs) to plan more effective health care delivery systems in the face of future unpredictable disasters.

2 | METHOD

The study was conducted in a tertiary referral centre, and participants were recruited from the specialized epilepsy outpatient unit of the neurology department. Patients were included consecutively if they fulfilled the inclusion and exclusion criteria. The study complied with the ethical guidelines of the hospital and was approved by the Institutional Ethics Committee (EC/OA-55/2021).

2.1 | Participants

The inclusion criterion was all adults (≥18 years of age) with epilepsy, and the exclusion criterion was patients with any known intellectual deficiency/cognitive dysfunction and/or psychiatric morbidity as per the record in the case file.

Each participant was explained at length the purpose of the study and signed an informed consent form.

2.2 | Survey questionnaire

Initially, a semi-structured interview schedule with open-ended questions was developed to provide the interviewers with a guide for the interview. The final structured questions were arrived at through a literature review, several consultations with subject experts consisting of epileptologists and neuropsychologists working in the epilepsy program monitoring unit and based on the responses from patients who participated in the pilot, semi-structured interview. The questions were translated into two local languages, Hindi and Marathi using language expert professionals following the forward-backward translation method. Training sessions were conducted that included mock interviews to ensure standardization of the interview process.

2.3 | Pilot study

For the pilot study, three trained neuropsychologists and a medical officer, who were proficient in those languages, conducted ten interviews following which amendments were made to the interview schedule. Any unclear or ambiguous question was rephrased to ensure greater clarity for the interviewees and elicit the information in a succinct manner. Content validity was established through expert consensus and an iterative process.

2.4 | Interview

The final structured questionnaire consisted of seven subparts that inquired about socio-demographic details, seizure-related issues, medical care, emotional well-being, impact on work, COVID-19 vaccination status, and PWE expectations of support during the pandemic.

A validated Indian socioeconomic scale[11] was used to classify the education, occupation and socioeconomic status of each participant. In-person interviews were conducted between June 2021 and October 2021, and participants answered the questions based on their experiences during the lockdowns enforced in the first and second waves of the COVID-19 pandemic in Mumbai. Additionally, a telephonic follow up was conducted at a later stage, after the interviews were completed, to track any shifts in attitude amidst changing public sentiment towards the vaccine. The follow up call was to understand the impact of the government's awareness efforts.

2.5 | Statistical analysis

Descriptive and inferential statistical analyses were conducted, and comparisons were made using IBM SPSS Statistics 22.0 software. Categorical variables are represented as frequencies/percentages and continuous variables as mean and standard deviation. A chi-square test of independence was conducted to examine the relationship between categorical variables.

3 | RESULTS

3.1 | Demographic characteristics

A total of 214 PWE participated in the study (Table 1). As per the classification on the Indian socioeconomic scale,[11] 99.6% belonged to the lower and middle socioeconomic classes with family monthly income ranging from INR 10 002-29 972 (USD 129-387) for an average family size of 4.9. The mean age was 32.5 ± 13.2 years, and the mean education was 10.6 ± 3.5 years. 50% of the sample was unmarried. 50% were employed, while 10% were homemakers and 16% were students (Table 1).

3.2 | Seizure variables

An increase in seizure frequency was reported by 20.6% and 5.1% reported an increase in seizure intensity.

3.3 | Medical care

3.3.1 | Antiseizure medications (ASMs)

Accessibility

Difficulties in accessing ASMs was reported by 28.9% of the sample (Table 2). The listed barriers were travel challenges amidst lockdown restrictions (57%), shut down of pharmacies (3%), inability to renew prescriptions (26%) and fear of going out due to high infection rates (2%).

TABLE 1 Demographic characteristics

Demographic variable	*N*	Percentage	Mean (SD)
Age (y)			32.5 (13.2)
Gender			
Male	117	55	
Female	97	45	
Education (y)			10.6 (3.5)
Occupation			
Employed	107	50	
Unemployed	51	24	
Student	34	16	
Homemaker	22	10	
Marital Status			
Unmarried	107	50	
Married	90	41.9	
Divorced	6	2.8	
Widowed	12	5.6	
Socioeconomic Status[a]			
Upper I	1	0.5	
Upper Middle II	16	7.4	
Lower Middle III	35	16.3	
Upper Lower IV	139	64.6	
Lower V	7	3.2	

[a]Indian Socioeconomic Scale.[11]

Availability

Barriers related to availability of ASMs at the pharmacies were reported by 30.5% of the sample. 28.3% who were migrant workers traveled back to their villages and reported unavailability of all medications.

Affordability

Half the sample could not afford the medications and reasons cited were reduced wages (4%) or loss of jobs (96%) in the pandemic. Another barrier was higher prices in neighborhood pharmacies as compared to the subsidized rates of the government hospital pharmacies.

3.3.2 | Medical consultations

Difficulty in following up regularly with their doctor was reported by 51% of the participants and barriers listed were lack of transport (30%), return to their villages (21%), shut down of hospital services (16.4%), fear of getting infected (13%), did not feel the need (9%), followed the old prescriptions (5.7%) and sealing off of the residential areas (4.9%). Only 7% of the participants consulted online and this was with physicians in private practice. The barriers for not accessing online consultations (Figure 1) were lack of sophistication and unavailability of these services at the government hospital.

TABLE 2 Challenges faced during the lockdown

Challenges	
Affordability	My relatives supported me by lending some money. I became weak because I had no money to even buy food". My father is a tailor and was unable to earn any money after the restrictions began. My family had one meal per day for weeks so that they could save money to pay for my medicines. The local pharmacist gave me medicines on credit, but I have not been able to pay him back even after months". My seizure frequency has increased, and my children and I have had to resort to begging. I'm worried for my children. I also need to get operated, but I do not have the money".
Accessibility	I had to walk for more than 5 kms to the hospital because no transportation was available. I could not travel to the hospital pharmacy, so had to buy medicines from a nearby pharmacy at higher rates. My seizures recurred after 4 years but I could not get medicines due to lack of prescription. We tried calling the hospital, there was no arrangement for doctors to talk to us on the phone.
Availability	I could not find medicines in the village. My friend working in a medical shop in the city couriered them to me. My entire village did not have medicines. My neighborhood pharmacy had limited stock and were able to give me medicines for only 2 weeks.

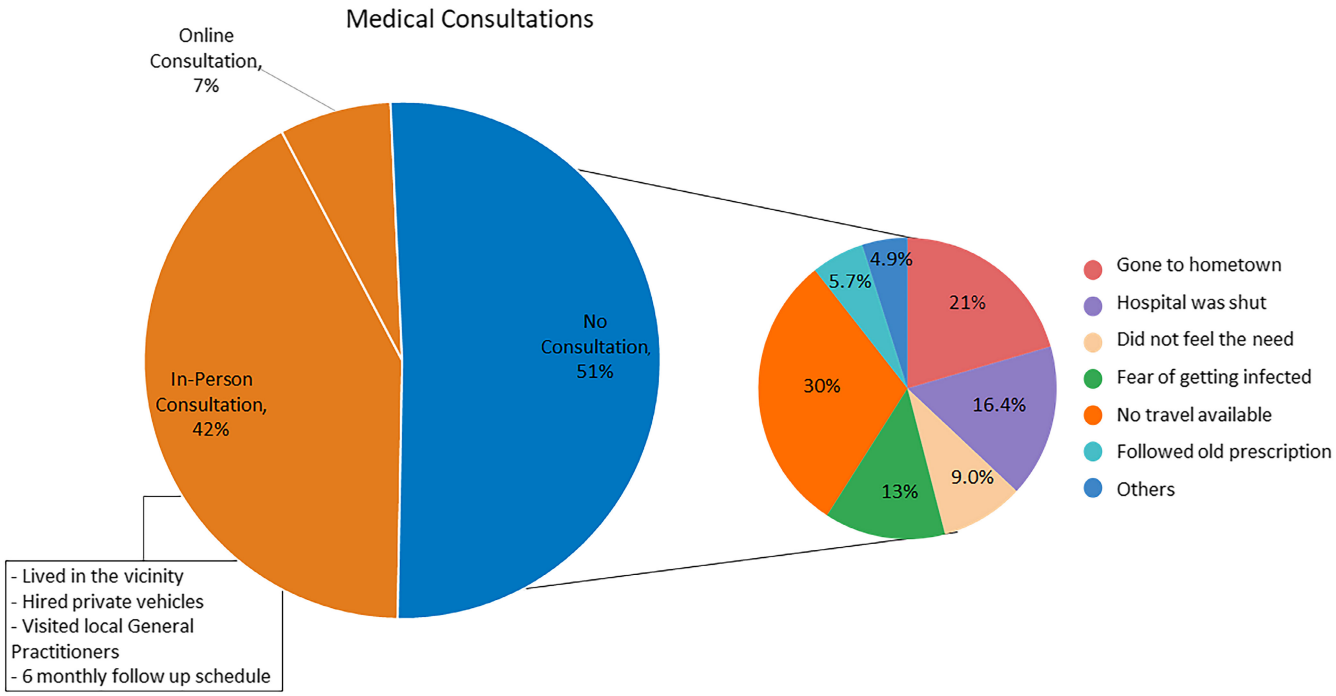

FIGURE 1 Medical consultations

3.4 | Well being

Worsening of mood was reported by 36.3% of the participants, with feeling low and anxious being the commonly reported mood issues. 29% reported an increase in seizure worry, 27% of the participants reported reduced energy levels and 17.7% reported worsening of sleep patterns (Figure 2). The relation between the increase in seizure frequency and worsening of mood and behavior was found to be significant ($P < .05$).

3.5 | Impact on employment

Out of the employed subgroup, 85.3% had loss of income with 53.0% of them losing their jobs and 32.3% receiving reduced remuneration. In the entire sample, 56% reported that a family member had lost a job (Figure 3).

3.6 | Vaccine hesitancy

Vaccine hesitancy was reported by 33.5% of the sample at the time of the survey and the reasons cited were concern about negative interactions with the ASMs, lack of information about the vaccine and distrust of the government program. In the follow-up after 6 months of the initial interview, more than half (52.05%) of the people who were initially unwilling had now taken both doses of the vaccine. In this group, many reported feeling more confident after seeing large numbers in the country getting vaccinated. Some had a change of mind due to the government vaccination awareness drives. 15.06% in this group continued to have reservations and the remaining 32% could not be contacted.

3.7 | Assistance during the pandemic

81% of the sample reported that they would have appreciated support from the government. 44% of this sample reported needing financial support and 39% wanted arrangements made for accessing medicines and doctors. 10% suggested that the government should have given special permissions for patients to travel during lockdowns to access medical care.

4 | DISCUSSION

In persons with epilepsy, the primary concern is seizure control. Several studies reported the impact of the pandemic on seizure frequency and found that around one-third of PWE had an increase in seizure frequency.[2,12–14] In the ILAE global survey, 22.8% of the PWE reported an increase in seizure frequency. Our study found that 20.5% of the participants reported an increase in seizure frequency and 29.3% reported significant seizure worry.

Several studies highlighted the role of increased mental burden with anxiety, depression and disturbed sleep being

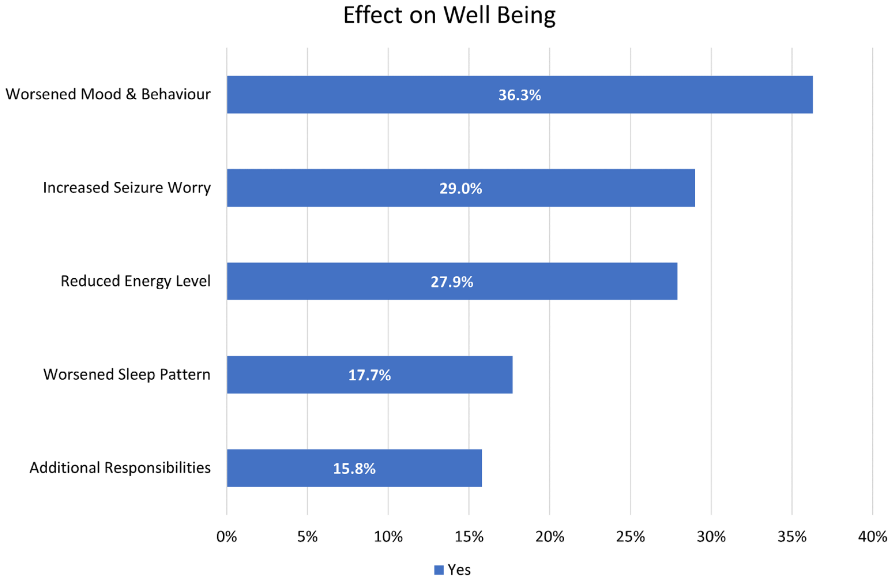

FIGURE 2 Effect on wellbeing

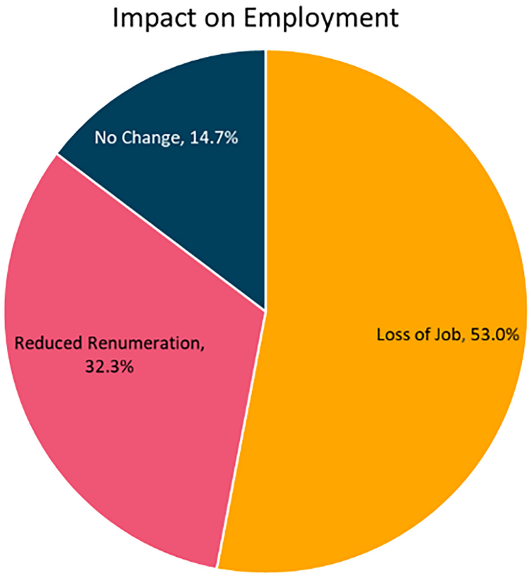

FIGURE 3 Impact on employment

commonly reported.[12,15–17] It has been postulated that these issues can increase the risk for seizures. We found increased seizure frequency as significantly associated with worsening of well being. These findings underscore the need for creating helplines and tele-counseling services. The services should be widely advertised and freely available for low-income PWE to receive support during the stressful pandemic phase.

In epilepsy, regular compliance with medication is important. During the pandemic, there were difficulties in obtaining medication. The ILAE report[2] mentioned least difficulties in a high-income country (HIC) (US 7.4%) and most difficulties in an LMIC (Philippines 48.6%). The challenges reported by most studies were unavailability of medication at the pharmacies and accessibility issues due to mobility restrictions.[12,13] Interestingly, in one city-based online survey in India, the majority reported no difficulty procuring ASMs or increased seizures due to non-availability.[18] However, in our study, one third complained of unavailability in the local city pharmacies. For those who had returned to their villages, there was unavailability of all medications. Lack of accessibility was primarily due to the inability to travel in the lockdown. The most challenging problem for half of the PWE was affordability. In a global survey on ASMs, the average retail prices for ASMs were not significantly different across countries despite the wide disparities in per capita income from HICs to low-income countries (LICs). The cost of ASMs was indicated as a significant problem by 80% of LMICs and LICs showing that affordability of drugs represents a significant barrier in many parts of the world.[19]

During the pandemic, the burden increased with loss of income. PWE and/or a member in the family lost a job, received reduced remuneration and were no longer able to access medications at subsidized rates offered by public hospitals. Some were unable to renew prescriptions so had to consult local private practitioners with increased expenses for the private consultations and buying the ASMs at local pharmacies. Other studies from LMICs also reported unaffordability as an important factor for poor compliance.[2,20,21]

Regular follow-up that is important for people with chronic conditions like epilepsy became a major challenge. In-person consultations were difficult due to travel restrictions, and there were limited arrangements for online consultations in government centres. Some reported hiring private vehicles at a high cost to visit the hospital while others visited local practitioners and paid for private consultations.

Studies conducted across the globe[22–25] highlighted the acceptability and usefulness of telemedicine as a critical tool for healthcare delivery during the pandemic. The pandemic tested the maturity of digital health resources in LMICs and the ability to use the same by low-income groups. Only 7% of our respondents reported that they had managed online consultations with private consultants. The majority were not aware, did not understand the concept of telemedicine and lacked sophistication required to access online services. More importantly, there was limited availability of telemedicine services by the government hospitals.

The participants were asked about their COVID-19 vaccination status. There was vaccine hesitancy in the low-income group in the early phase due to reservations about the government program and efficacy of the vaccine. Governments must have awareness programs to provide knowledge and address fears before rolling out a vaccine program. The majority of the PWE in the study reported wanting government assistance in the form of financial support and arrangements to access medical care.

The learning from this study can pave the way for future action (Table 3). The unique challenges for the low-income PWE during a pandemic are the unaffordability of medical care and the inability to access telemedicine services. It is critical to create systems that facilitate access to medications and consultations in the event of a lockdown. A study from Kuwait reported that 96% of their sample was compliant with ASMs, as the government had started home delivery of medications.[26] Miller et al[27] suggested giving prescriptions that were valid for longer periods, video telephone consultations and virtual support groups to help PWE cope with the stress.

During the pandemic, the government of India issued guidelines and set up telemedicine services.[28] However, reach of these services was limited for the low income group. Saleem et al from Pakistan reported that despite the government setting up a telehealth project, more than 90% of the respondents in their study were unaware of the same. The authors emphasized the need for creating awareness, especially for low educated rural populations.[20] In a recent study from India about the use of telemedicine during the pandemic, more than half (58.2%) of the sample was unaware of the facilities. But, in the group who did use the services, more than 95% reported satisfaction. Hence, in resource poor countries, it is important to first create awareness about the availability and benefits of telemedicine.[29]

The study had some limitations. The sample size was restricted due to the time intensive interview methodology. Data was collected from a single tertiary referral centre. The group interviewed were amongst the first to return to seek help when the sanctions were lifted and may not be entirely representative of all PWE who usually visit the hospital. No validated scales were used to assess mood changes. Mood was assessed by close-ended questions in the structured interview as low income PWE usually have challenges answering formal scales. The patient reported details could not be cross verified for a sub group who were unaccompanied by family members.

TABLE 3 Care for low income PWE

Challenges	Lessons learnt	Action plan governments, epilepsy and Global Health organizations
Affordability of ASMs	• Loss of income during pandemic leading to treatment gap • Poor compliance due to unaffordability may lead to increase in seizures	• System for distribution of free or subsidized medications
Accessibility to ASMs and Consultations	• Lockdown and restrictions in travel by public transport barriers to accessing subsidized medications from government hospitals. • Inability to renew prescriptions • Access telemedicine services	• Special travel permits during pandemic for medical purposes • Improving infrastructure to provide access to affordable telemedicine. • Hub-spoke telemedicine model for health care delivery to the rural poor. • Training of Doctors for Epilepsy Tele consultations • Guidelines for Epilepsy specific Telemedicine. • Awareness and training of low-income groups for accessing telemedicine services.
Impact on Wellbeing	• Mood and sleep disturbances due to pandemic related stress. • Increased stress may lead to increased seizure frequency	• Creating awareness • Setting up free helplines • Online counseling services

5 | CONCLUSIONS

The COVID-19 pandemic impacted the people with epilepsy from lower-middle income countries primarily due to the unaffordability of ASMs and lack of access to telemedicine care. COVID-19 is a reminder of the necessity of the digitalization of medical services. For increased internet penetration and usage by the low-income groups, the services need to be upscaled. Training of doctors and low educated users, explicit guidelines about privacy and data storage, and upgraded infrastructure need to be undertaken on a priority basis. There is a need to establish robust telemedicine hub-spoke models in LMICs wherein the urban government tertiary hospitals can be set up as hubs to deliver telemedicine and rural primary health care centres set up as spokes to receive the guidance.[28]

The voices of the low income PWE have been underrepresented. As we move into an uncertain future of possible further waves of the pandemic, it has become critical to represent the unmet health needs of the most vulnerable group of people with epilepsy and ensure that they receive adequate care and support.

AUTHOR CONTRIBUTIONS

Urvashi Shah: Conceptualisation and design (lead), writing original draft (lead), review and editing (equal), data interpretation (equal). Shivani Rajeshree: Data collection (equal), formal analysis and interpretation of results (lead), methodology (lead), review and editing (equal). Parthvi Ravat: Writing original draft (supporting), review and editing (equal). Mayuri Kalika: Data collection (equal), introduction (lead), review and editing (equal). Saloni Mehta: Data collection (equal), review and editing (equal). Antara Sapre: Data collection (equal). Sangeeta Ravat: Conceptualisation (supportive), review and editing (equal).

CONFLICT OF INTEREST

None of the authors has any conflict of interest to disclose. 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.

DISCLAIMER

The views expressed in the submitted article are the authors own and not an official position of the institution or funder.

ORCID

Parthvi Ravat https://orcid.org/0000-0001-9548-8704

REFERENCES

1. Bhaskar S, Bradley S, Israeli-Korn S, Menon B, Chattu VK, Thomas P, et al. Chronic neurology in COVID-19 era: clinical considerations and recommendations from the REPROGRAM consortium. Front Neurol. 2020;11:664.
2. Sureka RK, Gaur V, Gupta M. Impact of COVID-19 on people suffering with epilepsy. Ann Indian Acad Neurol. 2021;24(1):51–5.
3. Government of India, Ministry of Health and Family Welfare. Psychosocial issues among migrants during COVID-19. [Internet]. 2020 [cited May 21, 2022]. Available from: https://www.mohfw.gov.in/pdf/RevisedPsychosocialissuesofmigrantsCOVID19.pdf
4. World Health Organisation. Coronavirus Disease (COVID-19). Coronavirus disease (COVID-19) weekly epidemiological update and weekly operational update [Internet] [cited May 21, 2022]. Available from: https://www.who.int/emergencies/diseases/novel-coronavirus-2019/situation-reports
5. South Africa says it may be on brink of fifth COVID wave. Al Jazeera [Internet]. 2022 [cited May 21, 2022]. Available from: https://www.aljazeera.com/news/2022/4/29/south-africa-says-it-may-be-on-brink-of-fifth-wave-of-covid-19
6. Hong Kong turns to emergency powers for China help in COVID surge. Al Jazeera [Internet]. 2022 [cited May 21, 2022]. Available from: https://www.aljazeera.com/news/2022/2/24/hong-kong-china-help-covid-surge
7. China's Shanghai aims to end COVID lockdown by June 1. Al Jazeera [Internet]. 2022 [cited May 21, 2022]. Available from: https://www.aljazeera.com/news/2022/5/16/shanghai-says-it-will-return-to-normal-on-june-1
8. Beijing imposes new transit restrictions in bid to contain COVID. Al Jazeera [Internet]. 2022 [cited May 21, 2022]. Available from: https://www.aljazeera.com/economy/2022/5/4/china-beijing-imposes-new-transit-restrictions-in-bid-to-contain-covid
9. North Korea reports first COVID outbreak, orders lockdown. Al Jazeera [Internet]. 2022 [cited May 21, 2022]. Available from: https://www.aljazeera.com/news/2022/5/12/north-korea-reports-first-covid-outbreak-since-pandemic
10. China imposes new curbs amid worst COVID outbreak in two years. Al Jazeera [Internet]. 2022 [cited May 21, 2022]. Available from: https://www.aljazeera.com/news/2022/3/13/china-announces-new-curbs-amid-worst-covid-outbreak-in-two-years
11. Mohd SS. Modified Kuppuswamy socioeconomic scale updated for the year 2020. IJFCM. 2020;7(1):1–3.
12. Millevert C, Van Hees S, Siewe Fodjo JN, Wijtvliet V, de Moura F, Villela E, et al. Impact of COVID-19 on the lives and psychosocial well-being of persons with epilepsy during the third trimester of the pandemic: results from an international, online survey. Epilepsy Behav. 2021;116(107800):107800.
13. dos Santos LM, Marin de Carvalho R, Domingues AV, Carneiro R, Giacomini F, Valente KD, et al. Patients with epilepsy during the COVID-19 pandemic: depressive symptoms and their association with healthcare access. Epilepsy Behav. 2021;122:108178.
14. Sanchez-Larsen A, Gonzalez-Villar E, Díaz-Maroto I, Layos-Romero A, Martínez-Martín Á, Alcahut-Rodriguez C, et al. Influence of the COVID-19 outbreak in people with epilepsy: analysis of a Spanish population (EPICOVID registry). Epilepsy Behav. 2020;112:107396.

15. Fonseca E, Quintana M, Lallana S, Luis Restrepo J, Abraira L, Santamarina E, et al. Epilepsy in time of COVID-19: a survey-based study. Acta Neurol Scand. 2020;142(6):545–54.
16. Huang S, Wu C, Jia Y, Li G, Zhu Z, Lu K, et al. COVID-19 outbreak: the impact of stress on seizures in patients with epilepsy. Epilepsia. 2020;61(9):1884–93.
17. Casassa C, Moss R, Goldenholz DM. Epilepsy during the COVID-19 pandemic lockdown: a US population survey. Epileptic Disord. 2021;23(2):257–67.
18. Rathore C, Baheti N, Bansal AR, Jabeen SA, Gopinath S, Jagtap S, et al. Impact of COVID-19 pandemic on epilepsy practice in India: a tripartite survey. Seizure. 2021;86:60–7.
19. Pironi V, Ciccone O, Beghi E, Paragua-Zuellig H, Patel AA, Giussani G, et al. Survey on the worldwide availability and affordability of antiseizure medications: report of the ILAE task force on access to treatment. Epilepsia. 2022;63(2):335–51.
20. Saleem T, Sheikh N, Abbasi MH, Javed I, Khawar MB. COVID-19 containment and its unrestrained impact on epilepsy management in resource-limited areas of Pakistan. Epilepsy Behav. 2020;112:107476.
21. Nicoletti A, Todaro V, Cicero CE, Giuliano L, Zappia M, Cosmi F, et al. The impact of COVID-19 pandemic on frail health systems of low- and middle-income countries: the case of epilepsy in the rural areas of the Bolivian Chaco. Epilepsy Behav. 2021;118:107917.
22. Mostacci B, Licchetta L, Cacciavillani C, Di Vito L, Ferri L, Menghi V, et al. The impact of the COVID-19 pandemic on people with epilepsy. An Italian survey and a global perspective. Front Neurol. 2020;11:613719.
23. Sanabria Sanchinel AA, Escobar Pineda ES, Oliveros I, Perdomo Mendizábal AL, Lara Girón JC, Vega Zeissig E, et al. Telemedicina y epilepsia: experiencia asistencial de un centro de referencia nacional durante la pandemia de COVID-19. Rev Neurol. 2021;73(11):390–3.
24. Datta P, Barrett W, Bentzinger M, Jasinski T, Jayagopal LA, Mahoney A, et al. Ambulatory care for epilepsy via telemedicine during the COVID-19 pandemic. Epilepsy Behav. 2021;03(116):107740.
25. Willems LM, Balcik Y, Noda AH, Siebenbrodt K, Leimeister S, McCoy J, et al. SARS-CoV-2-related rapid reorganization of an epilepsy outpatient clinic from personal appointments to telemedicine services: a German single-center experience. Epilepsy Behav. 2020;112:107483.
26. Abokalawa F, Ahmad SF, Al-Hashel J, Hassan AM, Arabi M. The effects of coronavirus disease 2019 (COVID-19) pandemic on people with epilepsy (PwE): an online survey-based study. Acta Neurol Belg. 2022;122(1):59–66.
27. Miller WR, Von Gaudecker J, Tanner A, Buelow JM. Epilepsy self-management during a pandemic: experiences of people with epilepsy. Epilepsy Behav. 2020;10(111):107238.
28. Dash S, Aarthy R, Mohan V. Telemedicine during COVID-19 in India—a new policy and its challenges. J Public Health Pol. 2021;42(3):501–9.
29. Choudhary N, Chakravarty K, Kharbanda PS, Lal V, Baishya J. Satisfaction and effectiveness of tele-medicine in follow-up of people with epilepsy in a resource-poor setting during COVID-19. Epilepsy Behav. 2022;128:108569.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Shah U, Rajeshree S, Ravat P, Kalika M, Mehta S, Sapre A, et al. Challenges for low middle-income people with epilepsy during the COVID-19 pandemic: *Lessons learnt, call for action*. Epilepsia Open. 2022;00:1–9. https://doi.org/10.1002/epi4.12646