Epilepsy care delivery during COVID-19 in resource limited countries: A survey in collaboration with International Epilepsy Equity Group

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Abstract

Background: The impact of the pandemic has had worse effects in countries with already stretched healthcare resources. The study aim was to explore changes in epilepsy care delivery in resource-limited countries during and since the acute phase of the COVID-19 pandemic.

Method: A cross-sectional survey was conducted in 22 countries among health care providers (HCPs) caring for persons with epilepsy (PWE), in collaboration with newly formed global collaborators, the International Epilepsy Equity Group. Findings were compared based on World Bank Ranking (WBR) and HCPs' practice type. Data were analyzed using Chi-square tests ($\alpha = 0.05$) and pairwise multiple comparisons with $\alpha = 0.017$ (Bonferroni adjustment). Open-ended responses were analyzed using thematic analysis.

Findings: A total of 241 HCPs participated in the study. Of these, 8.30%, 65.98%, and 21.99% were from high-income (HIC), upper-middle-income (UMIC), and lower-middle-income countries (LMICs), respectively. Among HCPs, 31.12% were adult specialists, and 43.98% were pediatric specialists. During the acute phase of the pandemic, HCPs reported that the major barrier for PWE was difficulty reaching physicians/healthcare providers. Except for difficulty reaching physicians/healthcare providers (WBR P=0.01 HIC<LMIC), no other significant differences in barriers during the acute phase were observed. Since the acute phase of the pandemic, the major concern for PWE was fear of getting infected with the SARS CoV-2 virus. Significant differences in concerns since the acute phase included lockdowns (WBR: P= 0.03 UMIC<LMIC), fiscal difficulties (WBR: P<0.001 UMICs<LMICs, UMICs<HIC; practice type: P= 0.006 adult<others, pediatrics < others), clinic closure (WBR: P=0.003 UMIC<HIC; practice type: P= <0.001 adult<others, pediatric<others), and long waiting times (WBR: P=0.005, LMIC<UMIC, LMIC<HIC; practice type: P=0.006 pediatric<adults). Diagnostic services, including EEG, MRI, CT (practice type: P<0.001, adult<others; pediatric<others), and lab work (WBR: P=0.01 UMIC<HIC), were restricted. The telephone was the most reported teleconsultation method used. Except for SMS/texting (WBR P= 0.02 UMIC<LMIC), there were no significant differences in teleconsultation methods used.

Discussion: There is a high probability that the initial wave and consequent reduction of in-person care, restriction of health services, and fiscal difficulties affecting all involved in care deliver, led to disruption of epilepsy care. Additional support are needed in resource-limited countries to cope with future pandemics.

1. Introduction

Epilepsy is one of the most common neurological disorders, affecting more than 50 million people worldwide. The World Health Organization (WHO) estimates that 80% of persons with epilepsy (PWE) live in resource-limited countries where the treatment gap exceeds 75%. Sustained access to trained professionals, diagnostic services, healthcare facilities, and affordable antiseizure medications are among the many drivers of the epilepsy treatment gap [1]. A global survey conducted by the WHO reported that only 12% of countries have a specific budget allocated to neurological disorders, with none in the African region and only 4% in low-income countries globally. Further, the global median for the neurological workforce, which includes adult neurologists, pediatric neurologists, and neurosurgeons, is 11 per 100,000 population, but it is only 0.1 per 100,000 population in low-income countries compared with 7.1 per 100,000 population in high-income countries [2, 3].

The coronavirus infectious disease (COVID-19) pandemic has globally impacted care delivery for people living with chronic diseases, including epilepsy. Limitations in accessing care were accentuated in regions where the treatment gap was already a major issue [4]. This situation imposed unique challenges for PWE and placed them at risk of breakthrough seizures. The pandemic also opened the door to telehealth, an especially useful care delivery method for PWE living in resource-limited regions [5].

We searched the PubMed database from January 2020 to January 2022 for relevant articles related to access to epilepsy care during the COVID-19 pandemic. Search terms included: “epilepsy,” “COVID-19 OR pandemic,” “access to care,” AND “care delivery.” Few studies have reported the clinician’s perspective on epilepsy care during COVID-19. One study reported findings predominantly from Europe and other high-income countries, and another focused on care delivery specifically for pediatric patients [6, 7]. Other cross-sectional studies from India, Iran, Lithuania, Pakistan, the United Kingdom, and the United States uniquely explored the impact of the pandemic on access to care for adult or pediatric patient populations in their respective countries.[8-14] Previous studies reported increasing seizure frequency, difficulty accessing antiseizure medications, unintentional non-adherence, patients postponing planned visits, and increasing use of teleconsultation during the pandemic. However, these studies did not compare countries or practice settings, and examined barriers at a single time point in a rapidly changing pandemic.

Although the impact of the pandemic on PWE has been explored in several HICs, upper-middle-income countries (UMICs), and lower-middle-income countries (LMICs), several gaps continue to exist. First, most of these studies reported how treatment or care delivery was affected at one time point, making it difficult to determine varying barriers and concerns about access to care during and after the acute phase of the pandemic. Second, prior studies have not compared barriers and concerns during and since the acute phase of the pandemic across HICs, UMICs, and LMICs. Understanding differences helps advocacy groups identify areas in which additional resources should be allocated. Third, prior studies rarely examined healthcare providers’ (HCPs’) perspectives on how

the pandemic affected epilepsy care, and to our knowledge, no studies compared the perspectives of specialists and non-specialists from resource-limited countries. This is important, given that PWE in resource-limited countries often seek care from primary care providers. Thus, the purpose of this study was to explore changes in epilepsy care delivery in resource-limited countries during and since the acute phase of the pandemic. Specific aims were to examine differences across resource-limited countries based on World Bank Ranking (WBR) (i.e., LMICs, UMICs, and HICs) and practice type (i.e., adult specialists, pediatric specialists, and others) in 1) barriers to access to care during the acute phase of the pandemic, 2) concerns about access to care since the acute phase of the pandemic, 3) restricted diagnostic services, and 4) the use of teleconsultation methods to deliver care.

We operationalized resource limited countries as those with limited healthcare resources. The WBR is a crude method of determining health delivery and health resource allocation. For example, the WBR system negates true intra-comparisons between countries meeting criteria for high income (i.e., $14,460 GNI Barbados) and wealthier countries ($65,910 GNI USA).[15] Further, the fiscal impact of COVID-19 restrictions on tourism, the main source of income in many of these countries, also, directly and indirectly, affected care delivery [5]. Therefore, high income countries (HICs) included in this study can be identified as resource-limited HICs.

2. Methods

2.1. Development of the International Epilepsy Equity Group (IEEG)

A multidisciplinary, culturally diverse group of researchers from the United States (US) conceptualized and designed the study to explore the impact of the pandemic on epilepsy care in their native countries and those of their collaborators. A global collaborative group, the “International Equity in Epilepsy Group (IEEG),” consisting of healthcare professionals caring for PWE in multiple countries, was formed for the study. Through the IEEG, an often unidirectional approach with prominence of researchers in upper income countries was negated by a relatively novel shared bidirectional global group input with most collaborators from LMIC [16]. In this initial study of the IEEG, each designated country representative served as the site investigator responsible for identifying the appropriate ethical approach for data collection in their respective country. The group’s goal is to improve reciprocity and equity in clinical care, education, research, and advocacy between high and lower-middle-income countries, address potential social issues, and reduce disparities in care.

2.2. Study Procedures

We administered a cross-sectional, online survey to HCPs, including physicians, psychiatrists, neurosurgeons, clinical officers, and nurses caring for PWE in resource-limited countries. The survey was available between May 19 to August 25, 2021. The Qualtrics survey link and QR code to the survey (Spanish and English versions) were sent to HCPs in 22 countries by the IEEG country leaders via email and WhatsApp for local distribution. Participation in the study was voluntary, and compensation for participation was not provided. After reviewing the study information sheet explaining the purpose and nature of the survey, participants affirmed they were HCPs caring for PWE and completed the survey. The repository for data collection and statistical analysis occurred at

one site in the US. Ethical approval for this study was obtained from the Indiana University Institutional Review Board. No nurses participated in the study.

2.3. Measure

An 18-item survey (see supplementary file) was used to measure HCPs' perspectives on the impact of the pandemic on epilepsy care delivery. Research team members developed the survey in English and translated it into Spanish. Topics measured included: 1) demographic details of the participants (ex: country, years of experience); (2) general information about practice (ex: adult, pediatric, primary care) and setting (ex: urban, rural); (3) barriers and concerns during and since the COVID-19 lockdown; (4) best practices adopted to ensure continued patient care; and two open-ended questions on (5) advantages and disadvantages of teleconsultation; and (6) suggestions to improve access to care during a pandemic. HCPs were asked to identify from a list any of the barriers or concerns they observed among their PWE during clinical practice. The shortage of diagnostic service was reported as 'same as before,' slightly harder,' much harder,' difficult or impossible.' The use of teleconsultation method was reported as 'not using,' 'seldom,' and 'frequently.' We anticipated the survey would take 5-7 minutes to complete.

2.4. Statistical Analysis

The following definitions were used for this study. The "acute phase" was defined as the time when the participant's country was initially exposed to the pandemic, and the time since the acute phase was defined as the period since pandemic-related restrictions were imposed in the participant's country. The independent variables were WBR and HCP practice type. WBR were categorized as high income, upper middle income, and low-income countries. We categorized practice type based on HCPs specialist status and those most often cared for PWE in the clinical setting. Therefore, the HCP practice type was categorized as adult specialists (i.e., adult epileptologists and adult neurologists), pediatric specialists (i.e., pediatric epileptologists and pediatric neurologists), and other (i.e., primary care physicians, pediatricians, internal medicine providers, clinical officers/house officers, neurosurgeons, and psychiatrists). The outcomes of interest were: 1) barriers to access to in-person care during the acute phase, 2) concerns about access to care since the acute phase, 3) restricted diagnostic services, and 4) the use of teleconsultation methods to deliver care.
The source of all data reported in this study was obtained from the survey. Data analysis was performed with SAS v9.4 (Cary, NC). Outcomes were compared on each independent variable (WBR and practice type) via Chi-square tests using $\alpha=0.05$. When $\alpha<0.05$, pairwise multiple comparisons were conducted via Chi-square tests with $\alpha=0.017$ (Bonferroni adjustment).
Qualitative data analysis: Participants responded to open-ended questions in English, Spanish, and Chinese (on the English version of the questionnaire). Spanish and Chinese entries were translated to English by university affiliated translators. The analysis was conducted one team members with expertise in qualitative research using thematic analysis methods. Participant responses were read multiple times and inductively coded to identify potential categories and themes. These categories and themes were referred to the participant responses again and final themes were determined. The themes were discussed with the team members and consensus was reached on the identified themes.

3. Results

3.1. Demographics and General Information about Practice

A total of 285 HCPs from 22 countries started the survey. However, 44 were omitted due to stopping the survey prior to completing at least one outcome question, leaving N=241 participants for analysis. Among HCPs, 31.12% were adult specialists, 43.98% pediatric specialists, and 24.90% were other.

Table 1 describes participants by country and practice type. The majority of the HCPs in this study practiced in urban (97.5%) and public health (86.7%) settings. Over 47% of HCPs had >10 years of experience, and 28.6% had < 5 years of experience. Participants were from four regions (Africa 5.8%; Asia 31.5%; Caribbean 12.0%; Latin America 50.6%) with 8.3% of them from HICs, 66.0% from UMICs, and 22% from LMICs. Table 2 describes participants by WBR. The participants from countries classified as high-income were from Antigua & Barbuda, Barbados, and Trinidad & Tobago.

3.2. Access to Care Based on World Bank Ranking

Table 3 shows differences in access to epilepsy care during and since the acute phase based on WBR. During the acute phase, difficulty reaching physicians/healthcare providers significantly differed across countries (P=0.01), with LMICs (73.58%) reporting it as a concern more often than UMICs (62.26%) and HICs (35.00%). Although difficulty getting medication, difficulty reaching an urgent care facility, and medication availability were identified as major concerns in all WBR regions during the acute phase, there were no statistically significant differences.

Since the acute phase, significant differences in concerns were lockdowns (P=0.003) with LMICs (71.7%) reporting lockdown concerns more than UMICs (50.64%); financial trouble (P<0.001) with UMICs (21.79%) reporting these concerns less than LMICs (67.92%) and HICs (70.00%); clinic closures (P= 0.003) with UMICs (24.36%) reporting these concerns less than HICs (60.00%); and long waiting times at clinics (P=0.005) with LMICs (7.55%) reporting these concerns less than UMICs (24.36%) and HICs (40.00%). While barriers such as transportation disruption, fear of getting infected with CoV-2, and healthcare worker shortages were identified as concerns, no significant differences were found based on WBR.

A majority of HCPs (52.23%) reported that the shortage of diagnostic services was slightly harder since the pandemic. Shortages in diagnostic services such as MRI (52.73%), EEG (55.00%), and CT (24.55%), were reported with no significant differences based on WBR. However, there was a significant difference in shortage of lab work services (P=0.01), with UMICs (13.91%) reporting lower concerns than HIC (38.89%).

The majority of HCPs (52.53%) reported using social media for teleconsultation purposes during the pandemic. There were no significant differences in the usage of teleconsultation methods, such as internet social media, mobile apps, and telephone, based on WBR. However, there was a significant difference in the use of texting/SMS (P=0.02), with UMICs (7.28%) reporting a lower usage of this teleconsultation method than LMICs (13.33%).

3.3. Access to Care Based on HCP Practice Types

Table 4 shows differences in access to care during and since the acute phase based on HCP practice type (i.e., adult specialists, pediatric specialists, and other). During the acute phase, the most reported concern was difficulty reaching HCPs (61.41%). There were no significant differences in

difficulty getting medications, reaching an emergency department, and medication availability between the three HCP practice types.

Since the acute phase, the most commonly reported concern was fear of getting infected with COVID-19 (73.95%). Significant differences in concerns were financial difficulties (P=0.006) and clinic closures (P<0.001), with adult and pediatric specialists reporting these concerns less than other HCP practice types. Additionally, there were significant differences in long waiting times (P=0.006), with pediatric specialists (12.38%) reporting it less than adult specialists (31.08%).

All diagnostic procedures, including lab work and neuroimaging, were restricted due to the pandemic. Significant differences were found in obtaining CTs (P<0.001), with adult (21.43%) and pediatric (16.35%) specialists reporting this restriction less than other HCP practice types (43.64%). Although shortages in EEG and MRI services were observed, there were no significant differences between practice types. While a significant difference in obtaining lab works for PWE was reported overall among practice types (P =0.05), the significance was lost upon multiple comparison adjustments.

The most used teleconsultation method was telephones (61.50%). There were no significant differences between the use of different teleconsultation methods based on practice type. Overall, 16% (6.6% of the adult specialists; 10.4% of the pediatric specialists; 40.0% of other HCPs) reported not using teleconsultation methods, and 36.1% (42.7% of the adult specialists; 35.9% of the pediatric specialists; 28.3% of the other HCPs) reported seldom using it.

3.4. Qualitative Findings

A total of 191 participants responded to the open-ended questions. Most HCPs reported that teleconsultation was an effective tool to ensure patient and provider safety during the pandemic, facilitate access to care, and maintain continuity of treatment in PWE. Teleconsultation was identified as a safe way for care delivery during the pandemic. Nevertheless, respondents acknowledged that the main disadvantage was the inability to complete a comprehensive physical examination. Other reported disadvantages were the lack of personal interaction, the need for patients to have access to and be familiar with technology, and the absence of a standard reimbursement system. The three main themes identified as best ways to approach access to care issues were to 1) improve healthcare policies both at institutional and government levels, 2) improve and promote telehealth/teleconsultation, and (3) improve access to medication. Table 5 shows selected quotes relevant to these themes from participants from different parts of the world.

4. Discussion

Developing programs to reduce the treatment gap and improve the quality of life of PWE has been the priority of multiple organizations, including the WHO, the International League Against Epilepsy (ILAE), and the International Bureau for Epilepsy (IBE). The treatment gap varies depending on the region. For example, in LMICs, it can be as high as 100%, and in many HICs, it can be less than 10%, with higher gaps in rural areas within the country [17]. The COVID-19 pandemic worsened access to care and disrupted the already fragile healthcare systems in resource-limited countries where budget allocations are often non-existent or negligible [2, 18, 19]. Thus, it was prudent to focus this study on resource-limited countries. Further, the HCP practice type is an important consideration, as a large proportion of PWE in resource-limited settings seek treatment from primary care providers

or non-specialists. Therefore, our study is unique as it highlights differences between epilepsy specialists' and non-specialists' perspectives on the impact of the pandemic on epilepsy care.

The creation of an international group, IEEG, unique to our study, provided a platform to address research questions with equal capacity for involvement and implementation of shared ideas. In this non-hierarchal collaboration model, colleagues in their respective countries inquired about the pandemic's effects on epilepsy care to obtain the most accurate data in each region. The WHO and other multi-national bodies recognize the importance of locally-led research and LMIC inclusivity [20]. However, partnerships between HICs and LMICs are still often felt to be unequal [21, 22].

Our study is the first to solely focus on resource-limited countries and evaluate the impact of the COVID-19 pandemic on both pediatric and adult epilepsy care during and since the acute phase of the pandemic. The study demonstrated that PWE living in LMICs may have experienced more difficulties accessing care than those living in UMICs or resource limited HICs due to lockdowns and fiscal difficulties. Interestingly, long waiting times in the clinic and clinic closures were reported as concerns in HICs more than UMICs and LMICs. This may reflect the expectations of PWE living in already resource-limited regions. HCPs reported that the inability to complete a comprehensive physical examination was a disadvantage of teleconsultation. Diagnostic services are the foundation of effective and high-quality healthcare delivery [23]. The scarcity of these services in already resource-limited regions can hinder the ability to make appropriate diagnoses and accompanying treatment choices, thus widening the treatment gap.

During the acute phase, most HCPs reported that reaching a healthcare provider was the biggest barrier for PWE. This survey did not inquire about the availability of HCPs during the pre-pandemic period, but it is likely that a preexisting problem worsened during the pandemic. Moreover, most participants worked in urban settings. This was an expected finding, as the neurology workforce is often limited in rural areas in most countries, with most neurological and medical specialists working in urban settings. While health care systems in each country are unique, implementing measures to improve access to care is essential. These measures can include training locally available primary care providers, clinical officers, and nurses who can help cope with future catastrophes.

Access to medication is one of the major problems in resource-limited countries [1, 5, 24, 25]. An abrupt interruption of antiseizure medications can increase seizure frequency and cause life-threatening consequences [7]. Understandably, one of the major concerns across all regions and practice types was access to antiseizure medications. These findings are similar to studies conducted in the United States and Lithuania but contrary to those from India, which reported minor pandemic effects on procuring medication [8-10].

The COVID-19 pandemic also opened new avenues to improve access to care. Telemedicine greatly expanded during the pandemic. High-income countries have reported rapid increase [26], safety and effectiveness [27-30] in the use of telemedicine during the pandemic. Although there are limited reports from resource-limited countries, studies from India have highlighted the safety and effectiveness in using telemedicine [31, 32]. Our study shows that teleconsultation methods offered PWE a safe alternative and alleviated concerns about COVID-19 infections. Nevertheless, the use of technology is not without limitations. Participants in our study acknowledged major pitfalls, including the inability to conduct a comprehensive physical examination and the need for internet access. In

many resource-limited countries, especially countries in Africa, people remain unvaccinated against the virus, which places them at higher risk for future variants and neurological complications. Similar advantages and disadvantages along with a decision-making tree on the use of telemedicine during a pandemic has been proposed from the United States [33].

5. Limitations

Our study had limitations. Given that this was an online survey, trying to calculate the number of people who may have received the link and thereby the response rate is near-impossible. Using WBR as a surrogate for income or resources to deliver care may have been a relative weakness. Further, per populous, respondents from Latin America and the Caribbean were overrepresented, while respondents from countries in Asia and Africa were less represented. However, concerns were often similar. The neurology workforce in Africa is very limited. In addition, participants from Venezuela (n=9) were omitted in the WBR analysis because the country is currently in an unclassified category and does not fall under any ranking. Only 8.8% of participants were from HICs. Additional studies with larger samples from HICs are needed to examine differences in barriers and concerns further. Finally, the survey respondents were predominantly from urban settings. This may be because the majority of the trained healthcare professionals, especially in resource-limited countries, practice in urban settings. Although PWE from rural settings seek treatment from urban areas, it would be valuable to explore the perspectives of HCPs practicing uniquely in rural settings. Finally, the findings of this survey reflect on the HCP's understanding about barriers and concerns of PWE's in accessing care. There may be biases in HCP's understanding and a study among individuals living with epilepsy would be necessary to explore PWE perspective.

6. Conclusion

Studies including ours have reported several barriers that contributed to disruption in epilepsy care delivery across the globe during the pandemic. There is a high probability that the initial wave and consequent reduction of in-person care, restricted health services, and fiscal difficulties led to disruptions in epilepsy care. The impact of the pandemic has worsened the already existing access to care issues and our study demonstrated that PWE living in LMICs may have experienced more difficulties accessing care than those living in upper-middle-income or resource-limited high-income countries. It is possible that the pandemic has had a severe negative impact on epilepsy care globally, worsening the treatment gap. The fragile health care systems are less equipped to react to a pandemic. Therefore, it is important for local governments to create policies to facilitate access to care for PWE by empowering primary care providers, nurses, and other health aids. The availability of technology may reduce the treatment gap and lessen the time to care delivery in resource-limited settings [15].

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REFERENCES

1. World Health, O., *Epilepsy: a public health imperative*. 2019: Geneva.
2. Organization, W.H., *Atlas country resources for neurological disorders - 2nd ed*, W.H. Organization, Editor. 2017: France.
3. Ali, A. *Global health: epilepsy*. in *Seminars in Neurology*. 2018. Thieme Medical Publishers.
4. Mbuba, C.K., et al., *The Epilepsy Treatment Gap in Developing Countries: A Systematic Review of The Magnitude, Causes, and Intervention Strategies.* Epilepsia, 2008. **49**(9): p. 1491-1503.
5. Nicoletti, A., et al., *Treating People With Epilepsy in Rural Low-Income Countries Is Feasible. Observations and Reflections From a "Real Life Experience" After a Long Lasting Intervention in the Rural Chaco.* Frontiers in Neurology, 2018. **9**.
6. Wirrell, E.C., et al., *Care delivery for children with epilepsy during the COVID-19 pandemic: an international survey of clinicians.* Journal of child neurology, 2020. **35**(13): p. 924-933.
7. Cross, J.H., et al., *Epilepsy care during the COVID-19 pandemic.* Epilepsia, 2021. **62**(10): p. 2322-2332.
8. Rathore, C., et al., *Impact of COVID-19 pandemic on epilepsy practice in India: A tripartite survey.* Seizure, 2021. **86**: p. 60-67.
9. Puteikis, K., A. Jasionis, and R. Mameniškienė, *Recalling the COVID-19 lockdown: Insights from patients with epilepsy.* Epilepsy Behav, 2021. **115**: p. 107573.
10. Casassa, C., R. Moss, and D.M. Goldenholz, *Epilepsy during the COVID-19 pandemic lockdown: a US population survey.* Epileptic Disord, 2021. **23**(2): p. 257-267.
11. Thorpe, J., et al., *The impact of COVID-19 on epilepsy care: Perspectives from UK healthcare workers.* Epilepsy Behav Rep, 2021. **16**: p. 100487.
12. Asadi-Pooya, A.A., M. Farazdaghi, and M. Bazrafshan, *Impacts of the COVID-19 pandemic on Iranian patients with epilepsy.* Acta Neurol Scand, 2020. **142**(4): p. 392-395.
13. Saleem, T., et al., *COVID-19 containment and its unrestrained impact on epilepsy management in resource-limited areas of Pakistan.* Epilepsy Behav, 2020. **112**: p. 107476.
14. Albert, D.V.F., et al., *The Impact of COVID-19 on Epilepsy Care: A Survey of the American Epilepsy Society Membership.* Epilepsy Currents, 2020. **20**(5): p. 316-324.
15. Ali, A., et al., *Delivering epilepsy care in low-resource settings: the role of technology.* Expert Review of Medical Devices, 2021. **18**(sup1): p. 13-23.
16. Lahey, T., *Chapter 25 - The ethics of clinical research in low- and middle-income countries*, in *Handbook of Clinical Neurology*, J.L. Bernat and H.R. Beresford, Editors. 2013, Elsevier. p. 301-313.
17. Meyer, A., et al., *Global Dsparities in The Epilepsy Treatment Gap: A Systematic Review.* Bulletin of The World Health Organization, 2010. **88**(4): p. 260-266.
18. Kumar, J. and P. Kumar, *COVID-19 pandemic and health-care disruptions: count the most vulnerable.* The Lancet Global Health, 2021. **9**(6): p. e722-e723.
19. Nicoletti, A., 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 & Behavior, 2021. **118**: p. 107917.
20. Dye, C., Boerma, T., Evans, D., Harries, A., Lienhardt, C., McManus, J., Pang, T., Terry, R., Zachariah, R. *Research for universal coverage: The World Health report 2013*. 2013; Available from: https://www.afro.who.int/sites/default/files/2017-06/9789240690837_eng.pdf.
21. Crane, J., *Scrambling for Africa? Universities and global health.* The Lancet, 2011. **377**(9775): p. 1388-1390.

22. Franzen, S.R.P., C. Chandler, and T. Lang, *Health research capacity development in low and middle income countries: reality or rhetoric? A systematic meta-narrative review of the qualitative literature.* BMJ Open, 2017. **7**(1): p. e012332.
23. Wilson, M.L., et al., *The Lancet Commission on diagnostics: advancing equitable access to diagnostics.* The Lancet, 2019. **393**(10185): p. 2018-2020.
24. Organization, W.H. *Access to medicines: making market forces serve the poor*. 2017; Available from: https://www.who.int/publications/10-year-review/chapter-medicines.pdf.
25. Cameron, A., et al., *Mapping the availability, price, and affordability of antiepileptic drugs in 46 countries.* Epilepsia, 2012. **53**(6): p. 962-969.
26. Kuroda, N., et al., *Impact of COVID-19 pandemic on epilepsy care in Japan: A national-level multicenter retrospective cohort study.* Epilepsia Open, 2022. **7**(3): p. 431-441.
27. Datta, P., et al., *Ambulatory care for epilepsy via telemedicine during the COVID-19 pandemic.* Epilepsy & Behavior, 2021. **116**: p. 107740.
28. Conde-Blanco, E., et al., *Emergency implementation of telemedicine for epilepsy in Spain: Results of a survey during SARS-CoV-2 pandemic.* Epilepsy & Behavior, 2020. **111**: p. 107211.
29. von Wrede, R., et al., *Counseling of people with epilepsy via telemedicine: Experiences at a German tertiary epilepsy center during the COVID-19 pandemic.* Epilepsy & Behavior, 2020. **112**: p. 107298.
30. Willems, L.M., 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 & Behavior, 2020. **112**: p. 107483.
31. Nair, P.P., et al., *Video teleconsultation services for persons with epilepsy during COVID-19 pandemic: An exploratory study from public tertiary care hospital in Southern India on feasibility, satisfaction, and effectiveness.* Epilepsy & Behavior, 2021. **117**: p. 107863.
32. Panda, P.K., et al., *Feasibility and effectiveness of teleconsultation in children with epilepsy amidst the ongoing COVID-19 pandemic in a resource-limited country.* Seizure, 2020. **81**: p. 29-35.
33. Kuroda, N., *Decision making on telemedicine for patients with epilepsy during the coronavirus disease 2019 (COVID-19) crisis.* Frontiers in Neurology, 2020. **11**: p. 722.

TABLES

Table 1: **Details of participants by country and practice type**

	Adult Specialist n=75 (31.12%)		**Pediatric Specialist** n=106 (43.98%)		**Other** n=60 (24.90%)
	Neurologist	***Epileptologist***	***Neurologist***	***Epileptologist***	
Antigua & Barbuda		1 (1.33)			3 (5.00)
Barbados		1 (1.33)			12 (20.00)
Trinidad & Tobago			1 (0.94)		2 (3.33)
Argentina			20 (18.87)	2 (1.89)	
China	2 (2.67)		24 (22.64)	7 (6.60)	15 (25.00)
Colombia	19 (25·33)	8 (10.67)	5 (4.72)	1 (0.94)	3 (5.00)
Dominican Republic	1 (1.33)		1 (0.94)		
Ecuador		1 (1.33)	5 (4.72)	1 (0.94)	
Jamaica		1 (1.33)	1 (0.94)		1 (1.67)
Martinique/West French Indies	3 (4.00)		1 (0.94)		
Mexico	11 (14.67)	6 (8.00)	4 (3.77)		12 (20.00)
Peru		1 (1.33)	1 (0.94)		
St. Lucia					2 (3.33)
El Salvador	6 (8.00)	1 (1.33)	3 (2.83)		
Ghana	1 (1.33)		1 (0.94)		9 (15.00)
India			1 (0.94)		
Kenya	2 (2.67)				
Myanmar	4 (5.33)		3 (2.83)		1 (1.67)
Nicaragua	1 (1.33)				
Pakistan	1 (1.33)		18 (16.98)		
Tanzania			1 (0.94)		
Venezuela	4 (5.33)		5 (4.72)		

Table 2: **Participating country by World Bank Ranking**

World Bank Ranking	**Country**	**Population***	**Total participants** N=241 (%)
High-income	Antigua & Barbuda	97,929	4 (1.66)
	Barbados	287,375	13 (5.39)
	Trinidad & Tobago	1,399,488	3 (1.24)
Upper-middle-income	Argentina	45,195,774	22 (9.13)
	China	1,439,323,776	48 (19.92)
	Colombia	51,269,185	36 (14.94)
	Dominican Republic	10,847,910	2 (0.83)
	Ecuador	17,643,054	7 (2.90)
	Jamaica	2,961,167	3 (1.24)
	Martinique/West French Indies	375,265	4 (1.66)
	Mexico	128,932,753	33 (13.69)
	Peru	32,971,854	2 (0.83)
	St. Lucia	183,627	2 (0.83)
Lower-middle-income	El Salvador	6,486,205	10 (4.15)
	Ghana	31,072,940	11 (4.56)
	India	1,380,004,385	1 (0.41)
	Kenya	53,771,296	2 (0.83)
	Myanmar	54,409,800	8 (3.32)
	Nicaragua	6,624,554	1 (0.41)
	Pakistan	220,892,340	19 (7.88)
	Tanzania	59,734,218	1 (0.41)
Unclassified	Venezuela	28,435,940	9 (3.73)
**2020 population obtained from https://worldpopulationreview.com/*			

Table 3: **Responses by World Bank Ranking Regions** (n=232[a])

			n(%) Endorsing[c]			
Variable	Total N[b]	Overall	Lower Middle Income n_{poss}=53	Upper Middle Income n_{poss}=159	High Income n_{poss}=20	P-value[d]
Biggest Barriers in Accessing Care During Acute Phase of the Pandemic						
Getting medication	232	130(56.0)	24(45.3)	94(59.1)	12(60.0)	0.20
Reaching physician/healthcare provider	232	145(62.5)	39(73.6)	99(62.2)	7(35.0)	0.01, H<L
Reaching an ED/urgent care facility	232	49(21.1)	10(18.9)	34(21.4)	5(25.0)	0.84
Medication not available in pharmacy	232	73(31.5)	15(28.3)	51(32.1)	7(35.0)	0.82
Biggest Concerns in Accessing Care Since the Acute Phase of the Pandemic						
Lockdown	229	129(56.3)	38(71.7)	79(50.6)	12(60.0)	0.03, U<L
Transportation Disruption	229	121(52.8)	34(64.1)	78(50.0)	9(45.0)	0.16
Financial trouble - reduced income/money to travel	229	84(36.7)	36(67.9)	34(21.8)	14(70.0)	<0.001, U<L, U<H
Fear of getting infected with CoV-2	229	171(74.7)	40(75.3)	117(75.0)	14(70.0)	0.88
Clinic closure	229	68(29.8)	18(33.9)	38(24.4)	12(60.0)	0.003, U<H
Healthcare worker shortage	229	47(20.5)	11(20.7)	35(22.4)	1(5.0)	0.19
Long waiting times	229	50(21.8)	4(7.5)	38(24.4)	8(40.0)	0.005, L<U, L<H
Restricted Services due to the Pandemic						
Shortage of Diagnostic Services						
Slightly harder		117(52.2)	24(46.1)	81(52.9)	12(63.2)	
Very difficult, or impossible	224	56(25.0)	14(26.9)	41(26.8)	1(5.3)	0.24
MRI	220	116(52.7)	31(60.8)	73(48.3)	12(66.7)	0.14
EEG	220	121(55.0)	30(58.8)	82(54.3)	9(50.0)	0.77
CT	220	54(24.5)	16(31.4)	31(20.5)	7(38.9)	0.10
Lab work	220	41(18.6)	13(25.5)	21(13.9)	7(38.9)	0.01, U<H
Teleconsultation Method Used During the Pandemic						
Internet	217	106(48.8)	21(41.2)	79(52.3)	6(40.0)	0.30
Texting/SMS	217	24(11.1)	11(21.6)	11(7.3)	2(13.3)	0.02, U<L
Social media	217	114(52.5)	30(58.8)	78(51.6)	6(40.0)	0.41
Mobile app	217	9(4.1)	0	9(5.9)	0	0.13
Telephone	217	134(61.7)	26(51.0)	96(63.6)	12(80.0)	0.09

[a]Excludes n=9 participants from Venezuela.
[b]Total N per question varies due to some participants not answering every question.
[c]n possible is provided for each group. Depending upon the number of participants answering the question, n's per group will be slightly lower.
[d]P-value from Chi-square test, α= 0.05; Pairwise multiple comparisons conducted via Bonferroni adjustment, α= 0.017.
Acronym ED: Emergency Department

Table 4: **Responses by Practice Type** (n=241)

Question	Total N[a]	Overall	n(%) Endorsing[b] Adult Specialist n_{poss}=75	Pediatric Specialist n_{poss}=106	Other n_{poss}=60	P-value[c]
Biggest barriers in Accessing Care During Acute Phase of the Pandemic						
Getting medication	241	137(56·8)	48(64.0)	56(52.8)	33(55.0)	0.31
Reaching physician/healthcare provider	241	148(61.4)	45(60.0)	70(66.0)	33(55.0)	0.36
Reaching an ED/urgent care facility	241	49(20.3)	17(22.7)	15(14.1)	17(28.3)	0.08
Medication not available in pharmacy	241	78(32.4)	28(37.3)	28(26.4)	22(36.7)	022
Main Concerns in Accessing Care Since the Acute Phase of the Pandemic						
Lockdown	238	134(56.3)	42(56.76)	58(55.2)	34(57.6)	0.95
Transportation Disruption	238	126(52.9)	43(58.11)	55(52.4)	28(47.4)	0.47
Financial trouble - reduced income/money to travel	238	84(35.3)	21(28.4)	32(30.5)	31(52.5)	0.006, A<O, P<O
Fear of getting infected with CoV-2	238	176(73.9)	61(82.4)	71(67.6)	44(74.6)	0.08
Clinic closure	238	68(28.6)	19(25.7)	17(16.2)	32(54.2)	<0.001, A<O, P<O
Healthcare worker shortage	238	47(19.7)	16(21.6)	16(15.2)	15(25.4)	0.26
Long waiting times	238	52(21.8)	23(31.0)	13(12.4)	16(27.1)	0.006, P<A
Restricted Services due to the Pandemic						
Shortage of Diagnostic Services	233					0.81
Slightly harder		119(51.1)	38(52.8)	56(53.8)	25(43.9)	
Very difficult, or impossible		60(25.7)	18(25.0)	25(24.0)	17(29.8)	
MRI	229	120(52.4)	34(48.6)	57(54.8)	29(52.7)	0.72
EEG	229	126(55.0)	40(57.1)	50(48.1)	36(65.4)	0.10
CT	229	56(24.4)	15(21.4)	17(16.4)	24(43.6)	<0.001, A<O, P<O
Lab work	229	42(18.3)	9(12.8)	17(16.4)	16(29.1)	0.05
Teleconsultation Method Used During the Pandemic						
Internet	226	110(48.7)	35(47.9)	55(52.4)	20(41.6)	0.46
Texting/SMS	226	24(10.6)	6(8.2)	12(11.4)	6(12.50	0.71
Social media	226	120(53.1)	35(47.9)	59(56.2)	26(54.1)	0.55
Mobile app	226	9(3.9)	5(6.8)	2(1.9)	2(4.1)	0.25
Telephone	226	139(61.5)	43(58.9)	64(60.9)	32(66.7)	0.68

Abbrev: A=Adult Specialist; P=Pediatric Specialist; O=Other

[a]Total N per question varies due to some participants not answering every question.

[b]n possible is provide for each group. Depending upon the number of participants answering the question, n's per group will be slightly lower.

[c]P-value from Chi-square test, α= 0.05; Pairwise multiple comparisons conducted via Bonferroni adjustment, α= 0.017.

Table 5: **Selected quotes about telehealth use from qualitative findings**

	Themes	Country	Quote
Advantages	Patient and provider safety	Barbados	The risk of contracting COVID is reduced for patients using public transports, waiting in clinic waiting rooms, or waiting in lines at the pharmacy to collect medication.
		Argentina	It is safer for the patient and the doctor since it helps avoid travel and the waiting in the doctor's offices
		Ecuador	Families don't worry about contamination with COVID in the hospital
	Access to care	Argentina	It is especially useful for patients who must travel from remote areas. The patient is more comfortable at home, and it allows the doctor to know the environment in which the patient lives and develops.
		Colombia	It is a reliable method that improves access and communication with patients in remote locations, leading to better outcomes in the treatment of epilepsies
		Jamaica	It is cheaper for patients. It cuts transportation costs, especially for those living in rural areas who must travel to clinics in urban settings.
	Continuity of care	Myanmar	Telemedicine is an easy (for health care providers) and effective way of caring for epilepsy patients, especially for follow-up patients. It is low cost and can be done conveniently without the need to travel
		West French Indies	Shortened date of evaluations and best treatment adjustment
Disadvantages	Technology issues	Jamaica	Patient internet access and elderly unfamiliar with technology sometimes make the process quite slow.
		Colombia	Sometimes, it is difficult for technology naive patients to handle even the most basic telephone calls; for those patients it is ideal to have a face-to-face care, but it is not always feasible
	absence of standard remuneration system	Kenya	Lack of reliable internet access and affordability are disadvantages. Also, patients are not willing to pay professional fees after online consultations.
		Ghana	Poor internet services and lack of structured acceptable remuneration for services are disadvantages.
		Trinidad	There is hesitancy to pay for services
	Inability to complete comprehensive examination	India	With first visit cases, one may miss some subtle findings
		China	A lot of information is not complete. The judgment of the disease may not be comprehensive enough
			The doctor/patient bond should be examined; it would help with adherence to treatment.
Proposed measures to improve access to care	Improve healthcare policies	Mexico	They should implement good government strategies and give real support to health institutions that is not fictitious and not a political agenda.
		Colombia	The health system should skip the need for authorizations by insurers so patients can access consultations. In Colombia, this is the main obstacle that patients point out.
	Improve and promote telehealth/teleconsultation	Ecuador	Reinforcing the benefit of teleconsultation helps keep patients more stable and with fewer hospitalization requirement
		Argentina	Teleconsultation facilitated access to patients from remote areas and for patients who feared contamination. We resolved most of the consultations. Some patients were summoned for an electroencephalogram or MRI, and the rest of the care was continued by telemedicine
	Improve access to medicine	Columbia	We should improve contact with patients with the help of their insurer, guarantee delivery of medicines and reduce bureaucratic burden. The health system must send medicines to the patient's home
		Myanmar	I think we should establish a medication registry and systematic delivery networks for patients who face travel restrictions or are unable to get medicine locally.
	Training of HCPs	Venezuela	We need better access to medicines and to train primary care physicians about this pathology.