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The psychosocial impact of COVID-19 within the first six months of the pandemic on youth with epilepsy and their caregivers

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Objectives: We assessed the impact of COVID-19 on children with epilepsy and their families, focusing on epilepsy management, family routines, learning, and adherence to Centers for Disease Control and Prevention (CDC) pandemic guidelines (e.g., social distancing, mask wearing) within the first six months of the pandemic. Group differences in COVID-19 impact on families were also examined based on race and ethnicity, being medically and/or geographically underserved, and insurance status.

Methods: Participants (n = 131) included children with epilepsy and their families from two clinical trials. The Impact of COVID-19 on Pediatric Epilepsy Management (ICPEM) measure was developed and administered to caregivers online from April 2020 to September 2020 across four large pediatric hospitals. Administration of the ICPEM occurred both during routine study assessments and an additional acute time point to obtain information early in the pandemic (e.g., April and May 2020). Descriptive statistics and t-tests were used for analyses.

Results: Data indicate minor to moderate impact of COVID-19 on pediatric epilepsy management. Caregivers of children with epilepsy reported the most impact on education and social functioning. Adherence to CDC guidelines was reported to be high. Those having public insurance reported greater difficulties obtaining daily anti-seizure medications compared to those with private insurance.

Conclusions: This study presents important initial data regarding the impact of COVID-19 epilepsy management and daily functioning in children with epilepsy and their families. While the acute impact of COVID-19 restrictions appear to be mild to moderate, it is unclear what the long-term impact of the pandemic will be on families of children with epilepsy.

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1. Introduction

COVID-19 has significantly changed the lives of families across the globe. Vocational, social, healthcare, and family routines have been disrupted, and families have had to reorganize their lives. This “new normal” may include working from home, being furloughed or loss of a job, supervising children while working, supporting children during distance learning, accessing healthcare from a virtual platform, reducing spending due to lowered incomes, following public health directives, and more. These adaptations in routines have required significant behavioral changes, and are disproportionately affecting families who identify as racial and ethnic minorities [1]. Coupled with fears associated with COVID-19, the potential for significant stress and burden for any family is evident, especially for families who are already vulnerable and underserved, such as those who have children with epilepsy.

Epilepsy is a common, chronic neurological condition that affects 1% of the US population [2] and disproportionately affects children [3] (i.e., 750,000 youth). Childhood epilepsy is particularly burdensome to families, who must manage uncertainty, fear of
seizures, stigma [4] potential loss of consciousness, and ongoing seizures for 30–40% of children despite treatment [5]. In addition, children with epilepsy are 3–6 times more likely to have neurodevelopmental and/or psychological comorbidities than the general population and children with non-neurological conditions [6]. They are also at 4-fold increased risk of premature death, with higher risk linked to comorbidities [7].

Despite the heavy burden of epilepsy, children with epilepsy are an underserved population with many unmet medical and behavioral health needs [8–14]. More than half of children with epilepsy live in poverty [15–17] (i.e., household income < $36,000, 53% have public insurance [16], 32% live in rural locations [17], and 64% of their caregivers have low health literacy [15]). Individuals with epilepsy who have lower socioeconomic status, are African American, and live in rural locations are at increased risk of early death [17]. These disparities are likely due to lack of resources and access to comprehensive epilepsy care [18] as well as systemic issues (e.g., systemic racism).

To date, no published studies of the impact of the COVID-19 pandemic on children with epilepsy and their families in the US exist; however, papers have highlighted that barriers to self-/family management of pediatric chronic health conditions exacerbated by the pandemic may have a greater effect on underserved and vulnerable populations, such as children with epilepsy [19]. A few international studies provide insight into how individuals with epilepsy and their families are coping. For example, one study from China found a higher risk for psychological difficulties related to COVID-19 in persons with epilepsy compared to healthy controls [20]. Similarly, another study from China demonstrated that worry about the adverse effects of the pandemic on epilepsy-related issues was a risk factor for increased seizures [21]. Increased stress/anxiety and exacerbated depression during the pandemic lockdown were also notable risk factors for increased seizures in a Spanish population [22]. Caregivers of children with epilepsy from Spain reported seizure (14.1%) and behavioral (20.3%) deterioration in children with epilepsy during the COVID-19 lockdown [23]. They also reported that reduced access to epilepsy care providers (68%), loss of access to regular therapies (52%), economic problems (62%), and caregiver anxiety and depression (68%) contributed to seizure and/or behavioral deterioration.

Finally, a multi-country study revealed that, in individuals with epilepsy surveyed online, 20% reported difficulties obtaining anti-seizure medications (ASMs) and 50% screened positive for symptoms of anxiety and depression [24]. These few international studies provide empirical support that people with epilepsy and their families are indeed particularly vulnerable to the impact of the COVID-19 pandemic.

Given the differences in how the U.S. and other countries have responded to the COVID-19 pandemic, examination of the social, behavioral, and healthcare aspects of the COVID-19 pandemic on children with epilepsy and their families in the US is critical, with particular attention to potential health disparities for underserved families. To this end, we recently developed a 57-item survey to assess the impact of the pandemic on the management of pediatric epilepsy: the Impact of COVID-19 on Pediatric Epilepsy Management (ICPEM). On this basis, the primary aim of the current paper was to describe COVID-19 pandemic impact on epilepsy management (access to seizure medications, epilepsy care, daily management), family routines (parenting, caregiver emotional health, vocation), and learning in children with epilepsy and their families within the first six months of the pandemic. In addition, we wanted to examine differences in COVID-19 pandemic impact on families managing epilepsy who: 1) identify as racial and ethnic minorities versus families who identify as White: Non-Hispanic, 2), are medically and/or geographically underserved versus those who are not and 3) have public versus private health insurance.

2. Materials and methods

2.1. Participants

Participants were included from two large adherence intervention trials: 1) Epilepsy Adherence in Children and Technology (eACT) for children 2–12 years old and their caregivers (NCT03817229) and 2) Behavioral Economics and Adherence in Teens (BEAT!) for adolescents 13–17 years old (NCT03958331). Both studies utilize multi-site designs, and Cincinnati Children’s Hospital Medical Center approved the protocols and serves as the single Institutional Review Board for all sites. Children with epilepsy and caregivers were recruited during routine epilepsy clinic visits. The following broader inclusion and exclusion criteria were met for children: 1) age 2–17 years, 2) confirmed epilepsy diagnosis 3) ability to read/speak English, 4) no major comorbid neurodevelopmental or medical disorders (e.g., Autism Spectrum Disorder, Type 1 diabetes), and 5) no plan to wean ASMs. The eACT sample was also required to have an epilepsy diagnosis within the past 2 years.

2.2. Procedures

Participants were recruited from four tertiary pediatric hospitals (Cincinnati Children’s Hospital Medical Center, Nationwide Children’s Hospital, Children’s Hospital of Orange County, and Medical University of South Carolina). Eligible participants were identified by members of the study team in consultation with the child’s epilepsy care provider. After ensuring all study-related questions were answered during the screening process, caregivers, children, and adolescents signed informed consent, assent, and Health Insurance Portability and Accountability Act (HIPAA) releases. Participants completed a brief background questionnaire to assess demographic characteristics, including child age, race, sex, as well as caregiver marital status and education. Medical variables of interest, including epilepsy type, date of diagnosis, seizure frequency over the past 3 months, history of psychological conditions (e.g., anxiety, depression, behavioral disorders), and prescribed ASMs were collected via medical chart review by trained clinical research coordinators using the electronic health record. Additional questionnaires were also completed by participants as a part of the larger trials; however, for purposes of the current study, only the ICPEM will be presented.

All active participants who were enrolled in one of the two parent studies were contacted by the research team to complete the ICPEM at an acute time point. If the active participants had an upcoming, regularly scheduled study assessment, the ICPEM was integrated into that assessment point and all future assessments. Newly enrolled participants completed the ICPEM at all regularly scheduled study assessments (i.e., baseline, post-intervention, and three follow-up time points). Only one caregiver per family completed the ICPEM, and the first ICPEM completion was used in the current study.

2.2.1. Impact of COVID-19 on Pediatric Epilepsy Management (ICPEM) Measure

The 57-question ICPEM measure was developed to assess the impact of the pandemic on the families’ management of pediatric epilepsy. The instrument was created to examine 1) the impact of the COVID-19 pandemic on general resources (income, food, etc.), epilepsy management (access to and utilization of epilepsy care, medicine), family routines (social activities, parenting, vocation), and learning (access to and utilization of school-based resources). In addition to 2) adherence to COVID-19 precautions. Development of the ICPEM was an iterative process and included...
a review of existing COVID-19 measures and expert review (psychologists, pediatric nurse practitioner, epileptologist, classroom teacher, and special education teacher), including discussion and selection of content domains that were relevant and critical to include for children with epilepsy and their families. The response scale ranged from 1 “not at all” to 5 “a lot” for impact questions, 1 “not at all comfortable” to 5 “very comfortable” for comfort level on going places during the pandemic, 1 “never” to 5 “rarely” for engagement in the Centers for Disease Control and Prevention (CDC) guidelines for COVID-19, and 1 “very difficult” to 5 “very easy” for difficulty in accessing and using learning resources and services. Yes/no questions were also included in the measure.

Our iterative process resulted in a final instrument with 57 items to be completed by caregivers of children with epilepsy. An abbreviated 25-item version of the ICPEM was piloted in April–May 2020, which was early in the pandemic. These 25 items were created to measure the short-term and acute impact of the COVID-19 pandemic as it was unknown at the time how long the pandemic would last. The additional 32 items were added later to understand the longer term impact as it related to adherence to COVID-19 precautions and distance learning. Initial lockdowns or stay-at-home orders occurred at the following times in each state: March 16, 2020 (Ohio and California) and April 7, 2020 (South Carolina). School closures and the pivot to virtual learning for all three states occurred in March, 2020. Participants completed questionnaires electronically via REDCap, an electronic HIPAA-compliant data capture site. If the caregiver did not complete the ICPEM via REDCap, they were mailed a paper version with a self-addressed, pre-stamped envelope for completion, or it was completed with the research coordinators via phone.

2.3. Statistical analyses

Means, standard deviations, and frequencies were calculated on variables of interest. Independent samples t-tests were used to examine group differences on a set of key questions from the ICPEM. Racial groups were defined as White: Non-Hispanic compared to Minority (i.e., White: Hispanic, Black, Asian, Bi or Multiracial). For the eACT study sample, information on health insurance (i.e., public versus private) and whether the family lives in a geographic region that is defined as medically underserved or rural based on Health Resources and Services Administration (HRSA) maps was also obtained. Group differences based on insurance status and geographic region were examined for the eACT sample.

3. Results

Participant demographics and medical characteristics are contained in Table 1. Of note, additional questions were added to the ICPEM several months following the initial development of the measure as discussed above. As such, full data on the first 25 items were available for n = 131 participants and only n = 29 completed later items. In particular, 66 participants completed the measure at an acute time point (April-August 2020), while 65 participants completed the measure as a part of their study questionnaires during routine time points (May-September 2020). The ICPEMs were completed at the following times: April (n = 26), May (n = 53), June (n = 23), July (n = 16), August (n = 10), and September (n = 3).

Examination of items on the ICPEM indicated minor to moderate impact on epilepsy management and routines (Table 2). The most impacted areas were for the child's education and learning experiences (3.56 out of 5), caregiver's ability to complete tasks related to job/school (3.29 out of 5), and the family's engagement in social activities (3.85 out of 5). Comfort with engaging in daily routines was moderate to high; however, comfort was lower for going to restaurants, friends' houses, and the emergency room/urgent care compared to tasks that were more logistical (e.g. getting medicine from pharmacy or grocery stores) or did not require social contact (e.g., going outdoors). Engagement in COVID-19 CDC guidelines was fairly high (ratings > 4 of 5) for wearing masks indoors, keeping social distancing, and washing hands/using hand sanitizer. A majority of parents felt they had support and access to needed resources for distance learning; however, approximately 1/3 of parents reported worry about increased risk of contracting COVID-19 for their child with epilepsy.

Additional items not presented in Table 2 and only asked in a subset of participants (n = 29) included questions about the degree to which families were following stay-at-home orders early in the pandemic (52% endorsed “I stay home most of the time, except for outdoor activities or necessities”) and time spent in distance learning (35% of children spent 2–4 hours per day, with 31% stating the child received 0–2 hours for online teaching). When caregivers were asked how was distance learning compared to their usual school learning with respect to academics, 48% noted it was worse, 41% noted it was the same, and 11% noted it was better. Similarly, the impact of distance learning on emotions and behavior compared to being in the typical school environment was noted to be

| Table 1 |
| ---|
| Demographic data (n = 131). |
| N (%) or M ± SD |
| **Child Age (years)** | 10.5 ± 4.4 years (Range 2–17) |
| **Time Since Epilepsy Diagnosis (months)** | 19.6 ± 27.4 |
| **Child Sex** | |
| ▪ Females | 62 (47%) |
| ▪ Males | 69 (53%) |
| **Child Race/Ethnicity** | |
| ▪ White: Non-Hispanic | 93 (71%) |
| ▪ White: Hispanic | 9 (7%) |
| ▪ Black | 11 (8%) |
| ▪ Asian | 2 (2%) |
| ▪ American Indian | 1 (1%) |
| ▪ Bi/multiracial | 10 (8%) |
| ▪ Other: Hispanic | 5 (4%) |
| **Seizures in the Past Three Months at Baseline** | |
| ▪ Yes | 64 (49%) |
| ▪ No | 67 (51%) |
| **Seizure Type** | |
| ▪ Focal | 40 (31%) |
| ▪ Generalized | 80 (61%) |
| ▪ Unclassified | 11 (8%) |
| **Parent Caregiver** | |
| ▪ Mother | 110 (84%) |
| ▪ Father | 16 (12%) |
| ▪ Other Legal Guardian (e.g., grandmother) | 5 (4%) |
| **Parent Marital Status** | |
| ▪ Single | 16 (12%) |
| ▪ Married | 99 (76%) |
| ▪ Separated | 4 (3%) |
| ▪ Divorced | 9 (7%) |
| ▪ Living with Someone | 3 (2%) |
| **Insurance Status (n = 83)** | |
| ▪ Private | 47 (57%) |
| ▪ Medicaid/Public | 36 (43%) |
| **HRSA Map Geographic Designation (n = 83)** | |
| ▪ None | 49 (59%) |
| ▪ Rural | 7 (8%) |
| ▪ Medically Underserved | 17 (21%) |
| ▪ Both Rural and Medically Underserved | 10 (12%) |
Table 2
Descriptive data for the impact of COVID-19 on Pediatric Epilepsy Management measure.

| PART 1. How much has COVID-19 impacted... N = 131? | M (SD) | % yes |
|-------------------------------------------------|--------|-------|
| **General Impact (1=Not at all to 5=A lot)**     |        |       |
| 1. Your child’s education and learning experiences | 3.56 (1.41) |       |
| 2. Your living situation (for example, who lives with you, where you live) | 1.40 (0.96) |       |
| 3. Your family’s income                           | 2.13 (1.29) |       |
| 4. Your ability to get food or other resources (e.g., toilet paper) for your family | 1.86 (1.11) |       |
| **Epilepsy Impact (1=Not at all to 5=A lot)**    |        |       |
| 5. Getting daily epilepsy (anti-seizure) medicine from pharmacies | 1.21 (0.65) |       |
| 6. Getting epilepsy care when you needed it       | 1.37 (0.87) |       |
| 7. Getting other essentials related to epilepsy care, like epilepsy rescue medicine | 1.08 (0.42) |       |
| 8. Your family’s management of epilepsy           | 1.23 (0.67) |       |
| 9. My child taking his/her epilepsy medicine as prescribed in the past week | 1.43 (0.98) |       |
| **Changes in Routines (1=Not at all to 5=A lot)** |        |       |
| 10. Completing tasks related to your job/school   | 3.29 (1.49) |       |
| 11. Getting along with family members             | 1.78 (1.02) |       |
| 12. Taking care of your physical health (e.g., exercise, eating, sleeping) | 2.14 (1.20) |       |
| 13. Taking care of your emotional health (e.g., worries and mood) | 2.18 (1.16) |       |
| 14. Engaging in social activities or time with friends | 3.85 (1.26) |       |
| 15. Parenting your child with epilepsy            | 1.45 (0.90) |       |
| 16. Helping your child with school/learning activities at home | 2.61 (1.45) |       |
| 17. Engaging in “free time” or doing something that you want to do | 2.99 (1.34) | 105 (80%) |
| 18. Do you feel your school has been providing enough online or paper resources to continue educating your child at home? | | 105 (76%) |
| 19. Has the school contacted you to check on how online education is going for you and your child? | | 13 (10%) |
| 20. Did you avoid taking your child to the emergency room or urgent care due to seizures, although before COVID-19 you would have? | | 61 (47%) |
| 21. You/your child’s healthcare team had to cancel a routine in-person epilepsy clinic visit. | | 21 (16%) |
| 22. We had an in-person clinic visit.              | | 71 (55%) |
| 23. We had a virtual (over the phone or computer) epilepsy clinic visit. | | 3 (2%) |
| 24. Have you or anyone in your direct family been diagnosed with COVID-19? | | 42 (32%) |
| 25. Do you worry that your child is at increased risk for getting COVID-19 due to his/her epilepsy? | |       |
worse for 37%, similar for 48%, and better for 15% of children. Finally, caregivers reported that their children received the following resources from their child’s school early in the pandemic (e.g., spring 2020): website information (62%), classroom instruction online with teachers (45%), one on one instruction with teachers (21%), electronic school books (17%), hard copy books (14%), online assignments (86%), paper packets (41%), tablets/computers (48%), Individualized Education Plan (IEP)-related services online (10%) or via paper (7%), and wi-fi hotspots (10%). Twenty-one percent noted that these resources did not apply to their child (e.g., younger children in daycare or at home).

Selected items of interest from the ICPEM were used to examine group differences in the COVID-19 pandemic adjustment and impact. No significant differences were found on these items based on race/ethnicity (see Fig. 1) or geographic/living areas (see Fig. 2). However, a significant group difference (t (81) = −3.55, p < 0.001) was found between those with private health insurance versus public insurance (e.g., Medicaid) regarding the ability to obtain their ASMs from pharmacies within the first six months of the COVID-19 pandemic (Fig. 3). Specifically, families with public insurance reported COVID-19 having more of an impact on their ability to obtain their ASMs from pharmacies compared to those with private insurance. No other insurance group differences were noted for ICPEM items.

4. Discussion

Study results suggest that families of children with epilepsy have experienced pandemic-associated difficulties within the first six months of the pandemic in three key areas: 1) education and learning experiences, 2) ability to complete tasks related to job/school, and 3) engagement in social activities. These stressors are similar to those experienced by the general population in the US [25] and not specific to epilepsy. Somewhat surprising, and contrary to perceptions of epilepsy healthcare providers [26] was the finding that families did not experience a substantial impact or difficulty in epilepsy-related areas such as accessing epilepsy care and obtaining and taking daily prescribed ASMs. These data suggest potential resiliency, flexibility, and resourcefulness in these families. Further, findings suggest that epilepsy healthcare providers were able to follow the advice of the expert consensus recommendations [27] and pivot to create accessibility to high-quality epi-
lepsy health care through telehealth and other resources, even during the lockdown. Of note, three of the sites (two in OH, SC) were in areas of more moderate COVID-19 impact in regard to the number of cases initially (or “when the initial assessment was completed”). Caregivers of children with epilepsy reported feeling comfortable in their daily routines if they occurred in the home environment and did not involve social contacts with others (e.g., going to stores, restaurants, or meeting with friends in their homes), suggesting that families were heeding the advice of the CDC early in the pandemic to socially distance. Indeed, families of children with epilepsy reported high adherence to the general CDC guidelines, including wearing masks indoors, keeping socially distant, and washing hands/using hand sanitizer. Finally, it is notable that 32% of caregivers noted worrying about their children with epilepsy being at higher risk of COVID-19, highlighting the need for healthcare providers to provide reassurance regarding risk for children with epilepsy.

For the subset of participants who completed the more detailed questions about school/online learning, caregivers reported significant concern related to distance learning. For example, nearly half of the sample reported that distance learning was inferior to the usual school environment in regard to promoting academic
achievement and behavioral and emotional functioning. Undoubtedly, children without epilepsy have also experienced disruptions to their school and social routines over the past several months, which may have negative academic outcomes when evaluating reduction in hours of school [28–30]. Prior to the pandemic, children with epilepsy versus without epilepsy were more likely to have developmental, behavioral, emotional, learning, and socioeconomic difficulties [3,31,32]. In fact, 25–50% of children with epilepsy are diagnosed with learning disabilities [3,33], with 19% receiving special education services compared to 4% of matched sibling controls [34], and, up to 50% of children with epilepsy experience neurodevelopmental, cognitive, and/or behavioral symptoms [35]. Therefore, negative sequelae of the pandemic may be particularly pronounced for children with epilepsy based upon these baseline vulnerabilities. Longitudinal research (e.g., impact of pandemic following the initial six months) is needed to examine this possibility.

One healthcare disparity was noted in the present sample regarding young children with epilepsy. In our study, parents of children with public insurance reported greater difficulties during the pandemic in obtaining daily ASMs from pharmacies relative to parents of children with private/commercial insurance. While the reason for the difference in this study was not specifically assessed, several causes are possible. Research into possible pharmacy deserts found that 1 in 8 pharmacies closed in the United States between 2009 and 2015, with disproportionate effects in low-income neighborhoods [36]. Indeed, most patients in diverse and low-income communities fill their prescriptions at their medical clinic and not at a pharmacy in their community [37]. Because public insurance programs, like Medicaid, typically require minimal to no co-payments for these medications, inadequate time and transportation resources may be among the major obstacles to receiving filling prescriptions. Several interventions might be deployed to overcome these barriers and improve access to medications, particularly for families with low income. First, epilepsy healthcare providers could ask patients if they are having any difficulties in getting prescriptions filled locally and identify the specific risk factors. Second, prescribers could be encouraged to order prescriptions that are dispensed in the largest possible quantities (e.g., a 90-day supply versus a 30-day supply), thereby limiting refill frequency when possible [27]. Third, children with stable epilepsy could obtain refills from mail-order pharmacies [27] which often support 90-day supplies. Fourth, providers could encourage caregivers to utilize pharmacy-free delivery options that have been made available during the COVID-19 pandemic. Finally, epilepsy care coordination (i.e., between nurses, physicians, pharmacists) for patients, especially those who are underserved and taking multiple medications, could occur to synchronize refills ordered by the same or different prescribers [38]. Notably, in order to implement these proposed interventions regarding prescribing and dispensing epilepsy medication, administrative changes by Medicaid plans and state pharmacy regulators may be necessary.

Limitations of the present study are as follows. The sample consisted only of families participating in two ongoing randomized trials of interventions to promote adherence for epilepsy regimens at four academic medical centers. While our study featured considerable heterogeneity in regard to child’s age, socioeconomic background, and health status, one of the samples was a new-onset epilepsy group (<2 years since diagnosis) who was taking no more than two medications to treat epilepsy. Thus, the present sample may not be generalizable to children with chronic or treatment-resistant epilepsy. A comparison group of children without epilepsy may also shed light on the impact of COVID-19 on all children and adolescents. In addition, these data were gathered early in the pandemic, and parents may feel differently as the pandemic continues to place challenges on daily life. Our results may have differed if surveys had been completed only in the fall of 2020 when hybrid and in-person learning was more common. In addition, all results are based on caregiver self-report which may lead to under- or over-reporting of children’s behaviors or CDC guideline adherence. It should be noted that this study did not analyze healthcare utilization data for this time period to determine if there were any differences in clinic visits, emergency department visits, or unplanned hospitalizations.

Despite these limitations, the present study offers preliminary information from the ICPEM regarding the impact of the COVID-19 pandemic on children with epilepsy and their caregivers as well as how this population is adhering to CDC guidelines for COVID-19.
Future research directions include examining the psychometrics of the ICPEM, and more broadly, exploring the longitudinal effects of the pandemic on this population, including children’s self-report of their experiences during the COVID-19 pandemic. We hope this study will provide timely direction to improve pediatric epilepsy care and access to needed resources.

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Authors Contributions

All authors contributed to the (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, and (3) final approval of the version to be submitted.

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