

COVID-19 Experiences in the Developmental and Epileptic Encephalopathy Community

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Introduction

Because of wide-ranging medical conditions, people with Developmental Epileptic Encephalopathies (DEE), are at potentially greater risk of consequences from COVID-19 infection and may have heightened sensitivities to vaccination. We assessed the impact of COVID-19 infections in DEE patients and obtained data on vaccine uptake and concerns of caregivers.

Methods

An IRB-approved, web-based survey for caregivers of children with DEE was distributed in English via social media and DEE community advocacy groups between July 15 and September 15, 2022. This effort was initiated and coordinated by DEE-P (Developmental and Epileptic Encephalopathy-Project) Connections, an advocacy group supporting DEE families and research.

Respondent Demographics

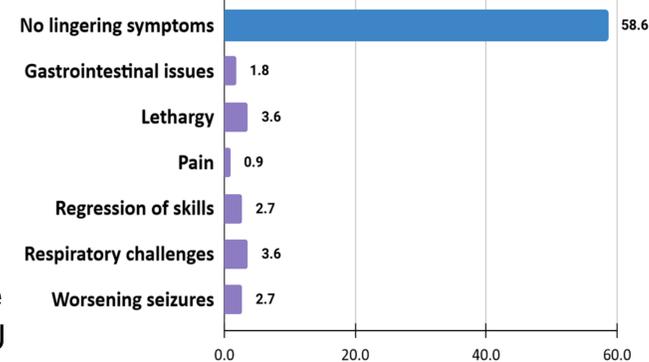
The 180 respondents reported living in North America (78%), Europe (16%) and 6% from other regions. Their children with a DEE represented 37 distinct disease groups—the most common were: KCNQ2, PCDH19, SCN8A, and SYNGAP1. Eighty-eight (56%) were female. Ages, in years, were <1 (2%), 1-3 (20%), 4-11 (42%), 12-16 (19%) and >17 (17%).

COVID-19 Illness

Our child is nonverbal and has limited communication skills so I can only go by what I saw.

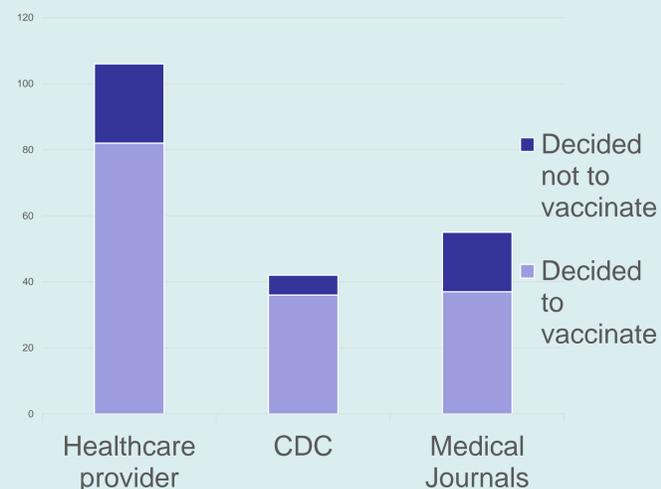
- 51% reported COVID mild cases 37% moderate, and 12% severe
- 80% of DEE children were unvaccinated when infected
- Fever, cough and congestion were the most common symptoms
- 13% required hospitalization, the majority of which were in the ICU 1 death was reported

Lingering COVID-19 Symptoms



COVID-19 Vaccine

IDENTIFIED SOURCES OF INFORMATION



- 60% of respondents vaccinated or intended to vaccinate their DEE child
- 71% had no side effects
- Reported side effects included fever, lethargy, soreness, and pain
- Increased seizures in 7 of 22 respondents reporting side effects
- Most side effects lasted 24-48 hours

Impact of COVID-19 on Families

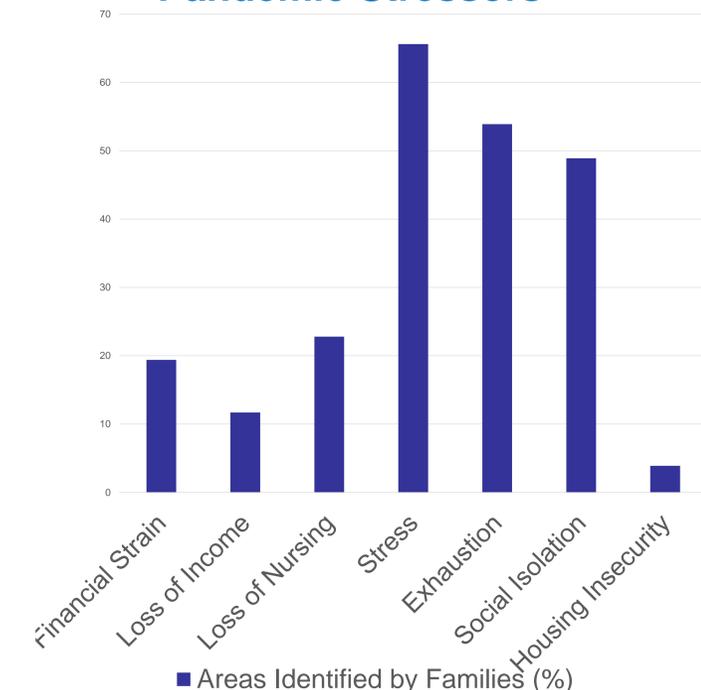
Telehealth allowed us to see doctors we would not have been able to see.

Because of virtual health visits, my child's diagnosis was severely delayed by at least 9 months.



Word cloud based on the question "How has the COVID-19 pandemic over the last several years impacted your child with a DEE?"

Pandemic Stressors



Conclusions & Future Directions

The effects of the COVID-19 pandemic on patients with DEEs have been wide ranging with rare—but serious—effects from the infection. The majority of parents/caregivers reported that their child with a DEE was either already or will be vaccinated; however, a sizable minority are either undecided or do not intend to vaccinate. Although this was a limited sample size, the data can help inform neurologists' discussions with DEE families about post-COVID-19 infection complications and vaccination concerns. Further investigations are needed - we aim to continue this work with further information gathering and discussions with DEE caregivers.

Funding

