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Research Paper

Impact of COVID-19 Pandemic on Developmental Service Delivery in Children With a History of Neonatal Seizures

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ABSTRACT

Background: Children with a history of acute provoked neonatal seizures are at high risk for disability, often requiring developmental services. The coronavirus disease 2019 (COVID-19) pandemic has led to widespread changes in how health care is delivered. Our objective was to determine the magnitude of service interruption of among children born between October 2014 and December 2017 and enrolled in the Neonatal Seizure Registry (NSR), a nine-center collaborative of pediatric centers in the United States. **Methods:** This is a prospective cohort study of children with acute provoked seizures with onset ≤ 44 weeks' gestation and evaluated at age three to six years. Parents of children enrolled in the NSR completed a survey about their child's access to developmental services between June 2020 and April 2021.

Results: Among 144 children enrolled, 72 children (50%) were receiving developmental services at the time of assessment. Children receiving services were more likely to be male, born preterm, and have seizure etiology of infection or ischemic stroke. Of these children, 64 (89%) experienced a disruption in developmental services due to the pandemic, with the majority of families ($n = 47$, 73%) reporting that in-person services were no longer available.

Conclusions: Half of children with acute provoked neonatal seizures were receiving developmental services at ages three to six years. The COVID-19 pandemic has led to widespread changes in delivery of developmental services. Disruptions in services have the potential to impact long-term outcomes for children who rely on specialized care programs to optimize mobility and learning.

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Introduction

Children with a history of neonatal seizures are at high risk for difficulties with motor and cognitive functioning at school age.¹ These children often receive developmental services (e.g., speech, occupational, and/or physical therapy) through public early intervention programs, the school system, and privately. The novel coronavirus disease 2019 (COVID-19) pandemic led to school shutdowns and limited in-person developmental services, disrupting therapeutic and educational delivery models across the United States in 2020 and 2021.^{2–4} Little is known about how restrictions to in-person services affected children with a history of neonatal seizures.

The Neonatal Seizure Registry is a multicenter collaboration of tertiary care pediatric centers in the United States who follow the American Clinical Neurophysiology Society guidelines for monitoring neonates with a high-risk of seizures.⁵ Since neonatal seizures are relatively uncommon (1 to 4 of 1000 live term births),^{6,7} multicenter data are necessary to understand the long-term neurodevelopmental outcomes. Our goal was to determine the impact of the COVID-19 pandemic on developmental service delivery among children with neonatal seizures who were enrolled at one of nine sites of the Neonatal Seizure Registry. We hypothesized that children enrolled in the Neonatal Seizure Registry would experience disruptions to their services as a result of the COVID-19 pandemic.

Materials and Methods

Children were prospectively recruited and enrolled in the Neonatal Seizure Registry, a nine-center collaborative of pediatric centers in the United States, which enrolled children from the following institutions: Mott Children's Hospital, Ann Arbor MI; Cincinnati Children's Hospital, Cincinnati OH; Children's National Hospital, Washington DC; Duke University, Durham NC; Massachusetts General Hospital for Children, Boston MA; Boston Children's Hospital, Boston MA; Children's Hospital of Philadelphia, Philadelphia PA; Lucile Packard Children's Hospital, Palo Alto CA; and UCSF Benioff Children's Hospital, San Francisco, CA.

Inclusion criteria

This was an ancillary study of the Neonatal Seizure Registry Developmental Functional Evaluation (NSR-DEV, NCT04337697). Children were eligible to participate in NSR-DEV if they had a history of neonatal seizures due to an acute provoked cause, had onset of seizures before 44 weeks postmenstrual age, and were between the age of three and six years at the time of follow-up assessment. Children who were enrolled in the NSR-DEV (NCT04337697) from June 2020 to April 2021 were included in the analysis. As part of the enrollment process, parents of the participants completed COVID-specific survey questions.

Medical history, including seizure etiology, was extracted from the medical records. The study was approved by UCSF Institutional Review Board, which acted as the single institutional review board for this multicenter study. A parent of each child provided written informed consent.

Parent survey

For each child enrolled in the Neonatal Seizure Registry, one parent or legal guardian was interviewed by a trained clinical research coordinator to determine whether the child was receiving developmental services. If a parent indicated that the child was

receiving developmental services, they were asked if the child received any of the following types of services: applied behavioral analysis, occupational therapy, physical therapy, speech therapy, vision therapy, feeding therapy, or other therapies. The parent was then asked if services were affected by the COVID-19 pandemic. If developmental services were affected, the parent was given the following choices of how developmental services were affected: service interruption, in-person services unavailable, change in service provider, or delays in accessing service providers. The parent had the opportunity to provide comments, as needed. The parent also provided demographic information (e.g., insurance type, maternal level of education, race, and ethnicity).

Statistical analysis

Statistical analyses were conducted using Stata 15 R statistical software, version 3.5.3 (Stat-Corp, College Station TX, USA). To characterize the sample, descriptive statistics was used to portray demographic characteristics of children who did and did not receive developmental services. We then tested for medical or demographic differences among children who did and did not receive developmental services using Fischer exact and chi-square tests. Finally, to determine if there were associations between types of disruption in developmental services to medical and/or demographic characteristics of the sample, we used univariate logistic regression modeling.

Results

Participants

A total of 144 children were enrolled in the study with the following acute seizure etiologies: hypoxic-ischemic encephalopathy, ischemic stroke, intracranial hemorrhage, infection, or other (e.g., hypoglycemia, kernicterus, unknown origin; [Table 1](#)). Of these children, half ($n = 72$ of 144, 50%) were receiving developmental services at the time of assessment. Children who received developmental services were more likely to be male and born preterm ([Table 1](#)). Children whose neonatal seizures were due to ischemic strokes or infections were more likely to receive developmental services compared with those with other etiologies. Conversely, children whose seizures were due to hypoxic-ischemic encephalopathy were less likely to receive developmental services ([Table 1](#)). Of the nine sites, eight had children who were receiving services. Within these sites, there was no difference in developmental services by site (median 53% of children at each site received services/total children enrolled by Neonatal Seizure Registry site, range 29% to 75%, $P = 0.48$). There were no differences in any other clinical characteristics tested among children who did or did not receive developmental services at the time of assessment.

Among the children receiving developmental services, most ($n = 46$ of 72, 64%) received more than one type of therapy. There were no significant differences in demographic or neonatal characteristics between children receiving one service or more than one service. Most of the children who had developmental services received speech therapy (53 of 72 [74%]) and more than half of the children received occupational therapy (45 of 72 [63%]) and physical therapy (41 of 72 [57%]) ([Table 2](#)). A minority of families ($n = 9$ of 72, 13%) reported that their children received "other services" ([Table 2](#)). These services included hearing services, emotional and behavioral therapy (not applied behavioral analysis), developmental therapy, music therapy, hippotherapy, and aquatic therapy.

TABLE 1.
Demographics and Seizure Etiology Among 144 Children Enrolled in the Neonatal Seizure Registry

Participant Characteristics	Total Number of Children Enrolled n = 144	Children Receiving Developmental Services n = 72	Children Not Receiving Developmental Services n = 72	P Value
Neonatal characteristics				
Male	77 (53%)	46 (64%)	31 (43%)	0.02
Preterm (<37 weeks at birth)	28 (19%)	23 (32%)	5 (7%)	<0.01
Race				
Black	15 (10%)	7 (10%)	8 (11%)	0.37
White	104 (72%)	53 (74%)	51 (71%)	
Other*	25 (17%)	12 (17%)	13 (18%)	
Seizure etiology				
Hypoxic-ischemic encephalopathy	65 (45%)	28 (39%)	37 (51%)	<0.001
Ischemic stroke	37 (26%)	22 (31%)	15 (21%)	
Intracranial hemorrhage	21 (15%)	8 (11%)	13 (18%)	
Infection	15 (10%)	10 (14%)	5 (7%)	
Other etiology†	5 (3%)	3 (4%)	2 (3%)	
Demographic characteristics				
Maternal education				
High school or less	16 (11%)	7 (10%)	9 (13%)	0.23
Some college	29 (20%)	13 (18%)	16 (22%)	
College graduate	57 (40%)	33 (46%)	24 (33%)	
Graduate degree	41 (28%)	15 (21%)	26 (36%)	
Insurance type				
Private	96 (67%)	47 (65%)	49 (68%)	0.72
Public	48 (33%)	25 (35%)	23 (32%)	
Follow-up characteristics				
Median age at follow-up, years (IQR)	4.2 (1.5)	4.2 (1.8)	4.2 (1.3)	0.40

Abbreviation:

IQR = Interquartile range

* Other race includes families who identify as Asian, more than one race, or who did not report race.

† Other seizure etiologies include hypoglycemia, kernicterus, and unknown origin.

Service disruptions

Of the children receiving developmental services, 64 of 72 families (89%) reported a change in services due to COVID-19 (Table 2). There were no differences in demographics, clinical characteristics, insurance type, or site among children who did and did not have service interruptions. The majority of families that reported a change in service delivery (47 of 64, 73%) disclosed that in-person services were no longer available during the pandemic. Children born term were more likely to have a service interruption because services were no longer available (n = 30 of 47, 64% for children born term), compared with children born preterm (n = 17 of 47, 36% relative risk 1.2, 95% confidence interval, confidence

interval 0.87 to 1.7). However, no other demographic or clinical characteristic had a significant association with type of service disruption.

Telehealth

Although not explicitly asked, most families (45 of 64 [70%]) reported that their child had at least one service transferred to telehealth. Four families (6%) declined telehealth services that were offered to them. Three families described telehealth to be “less effective” for their child than in-person services, and one family reported that telehealth was discontinued by the team and family because it was “too difficult for the child to participate.”

TABLE 2.
Type of Services Received and Reasons for Service Disruption During the COVID-19 Pandemic Among 72 Children Enrolled in the Neonatal Seizure Registry

Type of Developmental Services	Number of Children Receiving Developmental Services n = 72
Speech therapy	53 (74%)
Occupational therapy	45 (63%)
Physical therapy	41 (57%)
Vision therapy	11 (15%)
Feeding therapy	9 (13%)
ABA	4 (6%)
Other	9 (13%)
Receives >1 service	46 (64%)
Type of service disruption	Number of children with service disruption n = 64
Interruption to service schedule	37 (58%)
In-person services no longer available	47 (73%)
Change in service provider	3 (5%)
Delay in accessing services	7 (11%)

Abbreviations:

ABA = Applied behavioral analysis

COVID-19 = Coronavirus disease 2019

Discussion

In this multicenter study of children who survived acute provoked neonatal seizures, approximately half of survivors required neurodevelopmental services in early childhood, and the COVID-19 pandemic led to disrupted services for most of those children. There were no significant differences in clinical or demographic characteristics among children whose services were interrupted, except that children born term were more likely to have their services interrupted than children born preterm because in-person services were no longer available. Despite the regional differences in pandemic-related shutdowns across the United States, the effects of the pandemic were widespread, affecting the majority of children enrolled across the nine centers in the Neonatal Seizure Registry, representing a variety of regions across the country.

The Neonatal Seizure Registry provides an opportunity to study developmental outcomes of children with a history of neonatal seizures. Among children enrolled for childhood follow-up, half of the children, aged three to six years, received developmental services at the time of our survey. There was no significant difference in seizure etiology or preterm birth among males and females in the entire cohort of children enrolled in the Neonatal Seizure Registry ($P = 0.57$); however, children were more likely to receive services between ages three and six years if they were male or born preterm. Males born preterm are more vulnerable to long-term neurological and motor impairments after birth,^{8–11} which may be reflected in our sample of children who received developmental services. In addition, a high proportion of children with a neonatal seizure etiology of infection received developmental services at school age in our cohort. Neonatal seizures caused by infection are considered to have a higher risk for long-term adverse neurodevelopmental outcomes than hypoxic-ischemic encephalopathy¹² and may explain our findings. A higher proportion of children with ischemic stroke received developmental services in our cohort; children with ischemic strokes are often diagnosed with motor disorders such as unilateral cerebral palsy¹³ and receive developmental services to improve participation and functional abilities.^{14,15}

Although not explicitly asked in our survey, a majority of the families whose services were interrupted reported a shift to telehealth services during the pandemic for at least one of the therapies. Several of the families also reported that they believed that telehealth services were “less effective” than in-person services. In a similar study, slightly less than half of families of children receiving therapy services during a pandemic also reported low satisfaction with telehealth therapies for their children with special needs.² The pandemic negatively affected the well-being of children and parents,¹⁶ with the greatest mental health burden falling on caregivers of children with special needs whose in-person developmental services were discontinued.¹⁷ However, access to telehealth services for children with disabilities was positively associated with overall satisfaction with the family-provider partnership² and improved mental health of caregivers.¹⁷ The benefits of telehealth and the patient/family characteristics that determine which children will best respond to telehealth intervention are currently being studied.^{18,19} Although telehealth for developmental services is an approach that was developed in response to the urgent need during the COVID-19 pandemic, if it can be done effectively, its use may have broader applications. Telehealth may provide a solution for more equitable service distribution in families who cannot regularly attend in-person sessions²⁰ or in regions with less access to services. We did not specifically ask families if they had access to telehealth services and are therefore unable to determine if certain sociodemographic groups had equal exposures to telehealth during the pandemic. Future study directions looking

at access to telehealth during the pandemic and beyond would be of great value.

A limitation of our study is that the results of our survey may only be generalized to children who receive tertiary care in the United States, given the highly unique circumstances in the country at the time when our families were queried. Because access to developmental services can vary based on sociodemographic inequities,^{21,22} access to tertiary care centers may differ based on patient demographics and may have biased the sample that we accessed through the Neonatal Seizure Registry. Unfortunately, we did not have baseline data about children's access to developmental services before the pandemic because the children in our study were enrolled between June 2020 and April 2021, reflecting a period in which the COVID-19 vaccine was not yet widely available, and restrictions were variable based on geographic region. School and service closures due to the COVID-19 pandemic were widespread but were variable over time and by region, so the results of our survey may be difficult to contextualize at times when vaccines are more available and most schools have reopened. Yet, with the current reality of subsequent surges of variant infections, our data remain relevant.

Conclusions

In this cohort of children with a history of neonatal seizures, developmental service use was high. The majority of children using developmental services experienced disruption in service delivery, including absence of in-person services, service interruption, and delays in access. Longitudinal studies in this population are needed to better understand the long-term effects of neonatal seizures on child development, as well as the effects incurred due to the COVID-19 pandemic. As children are able to resume developmental services, intensive targeted and functional developmental therapies may be needed to mitigate the effects of service disruption in children with neonatal seizures.

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