


# How Providers in Child Neurology Transitioned to Telehealth During COVID-19 Pandemic

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## Abstract

To understand child neurology care practices in telehealth (TH), we conducted an online survey interested in identifying which patients should be triaged for in-person evaluations in lieu of telehealth management. We also sought to identify provider and patient/parent limitations of the TH experience. One hundred fourteen clinicians completed the online survey. The majority of child neurologists transitioned within 3 weeks of the pandemic onset and found it inappropriate to evaluate a child under 1 year of age via TH. We identified specific disorders considered inappropriate for initial evaluation via TH, including neuromuscular disease, neuropathy, weakness, autoimmune disease and autism spectrum disorders. Patient and parent technical and economic issues are significant limitations of TH. We suggest quality improvement measures to provide additional training, focusing on particular disorders and increased access for those patients currently excluded from or limited in using or accessing TH.

## Keywords

children, epidemiology, efficacy, outcome, behavior, neurodevelopment

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## Introduction

The COVID-19 pandemic thrust the world into the telemedicine era. When the World Health Organization (WHO) declared a global pandemic on March 11, 2020, many communities in the United States and worldwide went into lockdown, requiring social isolation to contain the spread of the SARS-CoV-2 virus. While the responses varied by state, medical providers across the country transitioned to telehealth (TH), often without specific training in the technical aspects or in adapting the traditional examination.

Before the pandemic some neurologists had successfully implemented TH to identify and evaluate specific disorders, notably acute strokes for emergent intervention and to screen for earlier diagnosis of autism spectrum disorders to expedite service provisions.<sup>1-6</sup> Studies reported successful TH implementation to train families in remote locations and with limited access to specialized clinics for behavioral techniques to address sleep, feeding and challenging behaviors.<sup>7,8</sup> TH has

been used to reduce socioeconomic and geographic disparities in the early identification of childhood neurodevelopmental disorders when financial and mobility constraints may limit

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medical care.<sup>7-9</sup> Other isolated populations such as residential facilities, psychiatric hospitals, rural communities, and prisons have benefited from TH as well.<sup>10-13</sup>

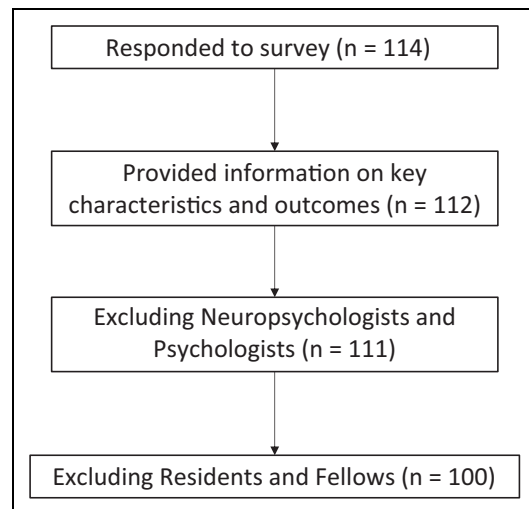
In the early months of the COVID-19 pandemic the Child Neurology Society published a resource toolkit providing guidance on the logistical implementation of telemedicine.<sup>14</sup> Subsequently, the Child Neurology Foundation circulated a survey to assess the Patient's Perspective of TH. At our institution, providers were required to take an e-learning module on telehealth using our newly implemented electronic medical record (EMR). Administrative teams quickly changed all scheduling templates to video visit templates and providers created note templates to meet the documentation requirements for telemedicine visits including an attestation created by our institution. Each provider was required to have a smart device (smartphone, iPad, or tablet) enabled with the appropriate EMR applications required to conduct the telemedicine visits. A large study led by the Division of Neurology at the Children's Hospital of Philadelphia analyzed 2,589 child neurology TH encounters performed during the pandemic. The results showed an effective conversion of outpatient care to TH encounters; a large percentage of providers rated these telemedicine visits as satisfactory with only a small proportion requiring near-term in-person follow-up.<sup>15</sup> There remained a gap of knowledge regarding what patient groups may be neglected in the TH transition.

We sought to understand how child neurologists responded to providing care during the COVID-19 pandemic; how providers prioritized conditions amenable to telehealth visits; and what difficulties were encountered with TH. We hypothesized that younger age patient groups would be preferentially triaged for in-person evaluations and sought to identify specific clinical diagnoses that were not considered appropriate for telehealth services. We were also interested in identifying other issues that may have limited TH to certain patient populations.

## Methods

An online survey in English, written and approved by the Columbia University Irving Medical Center's Institutional Review Board, was sent via email, using personal and professional contacts and social media platforms such as neurology specific Facebook groups. The survey was open from June 5, 2020 to June 29, 2020.

The survey, which took 5-10 minutes to complete, consisted of 4 parts: (1) Demographics, (2) Logistics, (3) Diagnoses and (4) Management. Question types were binary, multiple-choice, and Likert and included open comment fields when appropriate. Respondents reported sex, age group (30-39 years, 40-49 years, 50-59 years,  $\geq 60$  years), race/ethnicity (Hispanic; Non-Hispanic Black, Asian, Native Hawaiian or Pacific Islander, Multiple Races, or prefer not to answer; non-Hispanic White), position type (Attending physician, Nurse practitioner), practice type (academic hospital/medical center versus other), and specialty (epilepsy, general, or other (a combination of all other responses)). Respondents reported on conditions (seizure, ADHD, headache, developmental delay, abnormal movements, autism, autoimmune, weakness, other, neuropathy, and neuromuscular) and age groups (< 1 year, 1-5 years, 6-11 years, 12-17 years,  $\geq$



**Figure 1.** Sample selection.

18 years, all ages) appropriate for diagnosis or follow-up with telehealth, indicating all applicable categories.

## Results

Of the 114 respondents who completed the survey, 112 provided information about key characteristics (sex, age, practice type, specialty, race/ethnicity) and information on patient age appropriate for diagnosis and follow-up and/or patient condition appropriate for diagnosis and follow-up (Figure 1). We restricted the sample to attending clinicians and nurse practitioners ( $n = 100$ ). Respondents practiced in 25 U.S. states; 29% of respondents were from New York State. At the time of the survey 39 (35%) subjects resided in states that had not experienced the first peak of COVID-19 cases and 73 (65%) resided in states that had passed the first peak in COVID-19 cases. Only 20 respondents (20%) had used TH prior to the pandemic and 29 of 114 (25%) had had formal telehealth training prior to COVID. Participant characteristics were similar by pre-COVID telehealth experience status (Table 1).

Approximately 80% of providers who completed the survey had not used TH prior to the pandemic. The majority of child neurologists quickly transitioned to TH regardless of age, location, practice type or subspecialty (data not included). Half of the respondents reported transitioning to TH within 1 week of office closure and over 40% reported transitioning within 1 to 3 weeks of office closure. Only 5% reported a duration of greater than 3 weeks for transition to TH.

Respondents were asked whether certain age groups were inappropriate for evaluation using TH (Figure 2). Fifty-six percent did not find it appropriate to evaluate a child under 1 year of age; however, only 17% reported that TH would be inappropriate for follow-up in this age group. The remaining 45% and 83% of respondents reported that *any* age was appropriate for TH initial and follow-up evaluations, respectively.

Respondents were asked whether specific conditions were appropriate to diagnose on an initial or follow-up TH encounter

**Table 1.** Survey Respondent Characteristics.

Clinician characteristics*	Total sample (%)	No pre-COVID telehealth experience (%)	Pre-COVID telehealth experience (%)
n	100	80	20
Sex			
Female	86	85	90
Male	14	15	10
Clinician age			
30-39 years	38	39	35
40-49 years	46	45	50
50-59 years	12	14	5
≥ 60 years	4	3	10
Race/Ethnicity			
Hispanic	12	15	0
Non-Hispanic	25	24	30
Black, Asian, Native Hawaiian or Pacific Islander, Multiple Races, or Prefer Not to Answer			
Non-Hispanic White	63	61	70
Position type			
Attending physician	96	96	95
Nurse Practitioner	4	4	5
Practice type			
Academic hospital/ Medical center	78	80	70
Other	22	20	30
Specialty			
Epilepsy	40	41	35
General	29	28	35
Other	31	31	30

\*Respondents reported on sex, age, race/ethnicity, position type, practice type and appropriateness of telehealth for diagnosis and follow-up based on patient age and/or condition.

(Figure 3). Fewer than 10% of respondents considered neuromuscular disease, neuropathy, and weakness as appropriate for initial diagnosis on TH. Only 12% and 40% of individuals thought that autoimmune disorders and autism spectrum disorders, respectively, could be appropriately diagnosed on an initial TH encounter. For every diagnosis a larger percentage agreed that TH was appropriate for follow-up evaluations for all of these conditions.

Respondents were asked whether their own referral and evaluation practices had changed during TH; for example, were they more or less inclined to refer for testing, such as recommending brain imaging, lab tests, lumbar puncture, EEG, or EMG/NCS. In general, most providers reported being less inclined to make each of these referrals (data not shown).

Eighty-nine percent of respondents reported that patients or parents experienced some difficulty accessing TH during the COVID-19 pandemic (Figure 4). Forty percent of respondents noted economic issues while 88% reported technical problems.

Of note, we did not define “economic issues” to the respondent, so this may have different interpretations, spanning from access to video-recording phones and high-speed internet usually required for connecting to TH visits. Twenty-nine percent (29%) of respondents noted that parents/patients had beliefs that telehealth was less effective than in-person evaluations and another 8 (7%) reported parent/patient concerns about TH security and privacy. Despite these difficulties, 97 (85%) of respondents planned to use TH after the COVID-19 pandemic; this was noted across ages, practice types, timing of the state relative to first pandemic peak, and specialty (data not shown). Notably, just over half (58%) of respondents reported using interpreter services during TH visits.

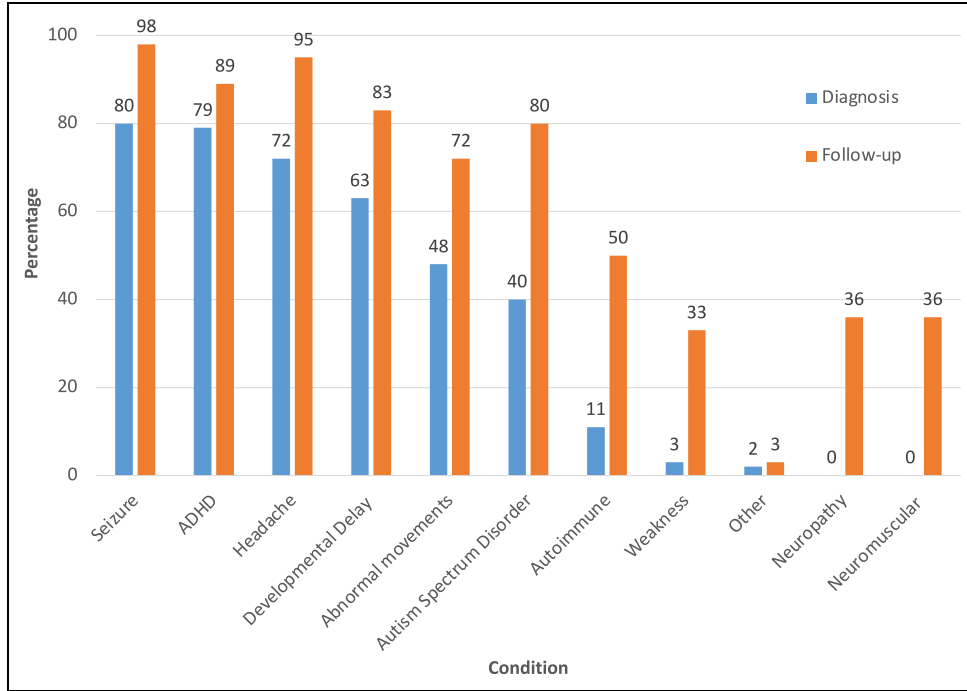
## Discussion

This study reports data from a June 2020, online survey across the US and Canada about TH implementation during a global pandemic. To identify specific gaps in care and limitations of TH for child neurologists, we asked the respondents about their experience with TH for diagnostic and follow-up appointments and patient/parent access to TH during the COVID-19 pandemic. Furthermore, we will propose strategies to address these gaps.

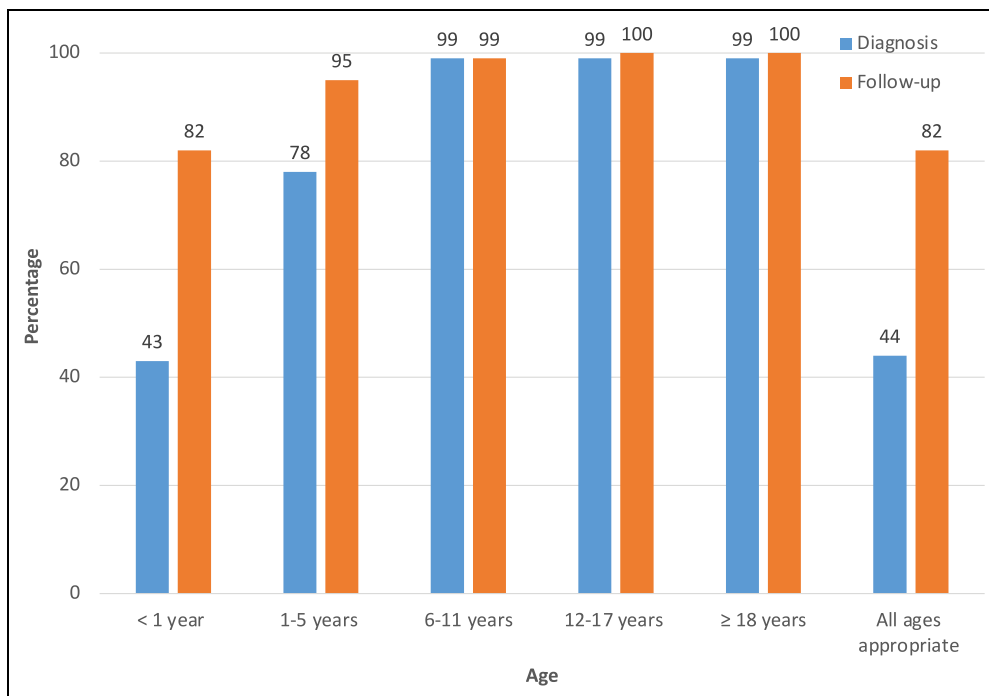
The majority of responding child neurologists transitioned quickly and felt most TH evaluations were satisfactory, but more appropriate for follow-up visits than initial consultations. Regarding the efficacy of TH for child neurology care, 71% responded that TH was at least as effective as in-person evaluations while only 25% found it to be less effective than in-person evaluations. This is consistent with the findings of Rametta et al., (2020) who reported that TH was “satisfactory” in 93% of visits. More importantly, almost 90% of respondents had experienced significant technical issues with the TH visits. Despite all the preceding issues at least 70% of respondents were satisfied with the TH experience. Importantly, our study identified specific patient groups that may not be appropriately managed with the shift to TH implementation.

Respondents did not find it appropriate to evaluate a child under 1 year of age using TH. Specific disorders were considered inappropriate for initial evaluation, including neuromuscular disease, neuropathy, weakness, autoimmune disease and autism spectrum disorders.

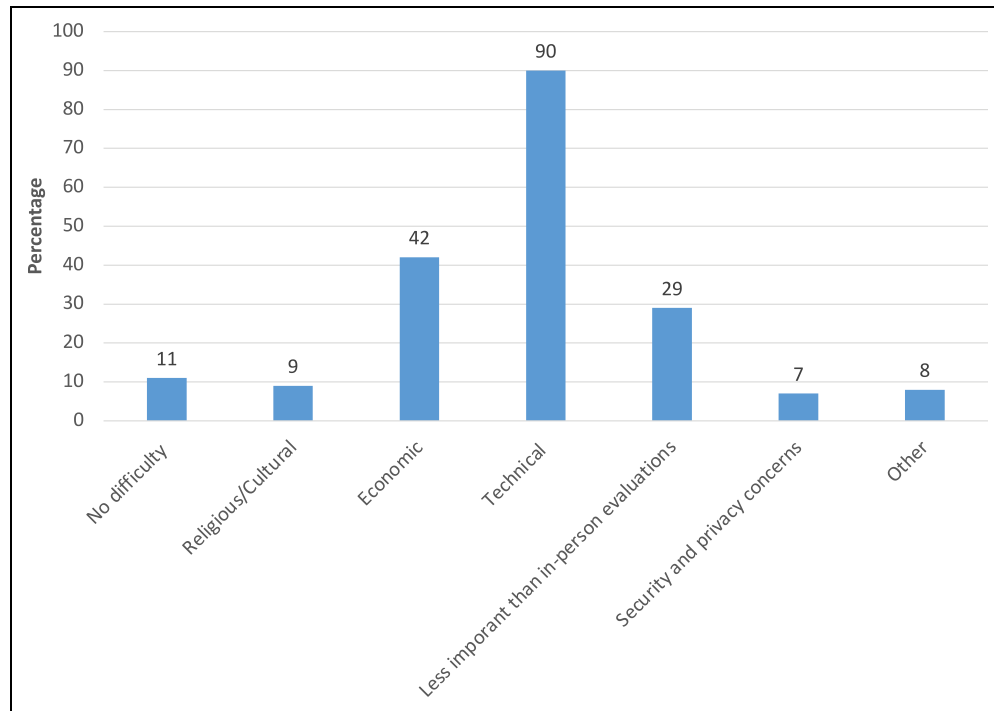
While much of the pediatric neurological exam is based on detailed, careful observation, there may be difficulties in identifying subtle neurological abnormalities and having the patient execute more complex movements using TH. Furthermore, aside from the technical, personal and economic limitations, TH may lead to the loss of the healing relationship associated with the physical examination and the “laying on of hands.” Lost is the incorporation of natural body language when there is pain or discomfort. Using a small viewing screen, the clinician only sees a “piece” of the patient and family and may miss the psychodynamic relationship between them. Many children need to develop a relationship or rapport with the practitioner before they will demonstrate their true capabilities.



**Figure 2.** Conditions appropriate for initial evaluation or follow-up via telehealth. n = 100 respondents reported on all conditions for diagnosis or follow-up.



**Figure 3.** Ages appropriate for diagnosis or follow-up on telehealth. n = 99 respondents reported on all ages for diagnosis and follow-up.



**Figure 4.** Factors influencing patient or parental difficulty in accessing telehealth during the COVID-19 pandemic. n = 100, respondents selected as many factors as applicable.

TH has brought new, unresolved economic issues such as the uncertainty about continued payments for these visits by insurers. At present we do not know if or how reimbursement rates for TH will change in the future. In addition, the use, staffing and configuration of physical offices may change if a significant portion of visits are conducted by TH. If practices require providers to work from home instead of offices, other serious issues, including childcare for practitioners will need to be addressed.

This survey yielded responses from 117 child neurology practitioners/trainees who represent < 1% of child neurologists in the U.S.<sup>16,17</sup> The respondents were overwhelmingly women, middle aged, and non-Hispanic white. The majority were in academic medicine and in the early to middle stages of their careers. Importantly, this convenience sample, was distributed via social media, which may have resulted in a selection bias toward individuals who are more inclined to work with TH and who had access to and experience with these technologies. This bias may have contributed to the 20% of respondents who had previously utilized TH in the practice prior to the pandemic, and the true percentage may be much lower. Importantly, we did not elicit information about the satisfaction from providers (or patients) with the new TH platform, nor did we analyze the distribution of new and old patient visits or ICD / CPT codes in comparison to prior to the pandemic, which could have been significant. We did not include survey questions regarding the child's physical/neurological exam and findings that were not adequately available through TH such as vital signs (especially for those on medications), funduscopic exams (for those with

headaches or TBI), tone, strength and reflexes (for those with neuromuscular, weakness and/or spasticity). Lastly, we did not specify economic issues in more detail, but certainly recognize that there is a growing digital divide in resources for individuals and communities who have been unable to maintain standard of care with the transition to the virtual platform.<sup>18-20</sup> Future studies may further investigate these disparities and identify economic and other logistical barriers to providing health equity across the population.

Future studies need to address the latter, since most providers are eager to continue using TH after the pandemic. This survey did not address quality of TH care nor potential disadvantages of TH, including concerns about patient access to TH platforms and understanding of the use of technology such as internet accessibility.<sup>4</sup> Patients' homes may lack appropriate lighting with extraneous distractions which can reduce the quality of the encounter. Personal, socioeconomic, and/or religious factors may also influence the patients' utilization and providers' acceptance of TH. The need for translation services may impose additional barriers; our survey noted that less than half of providers used translator services. Privacy and security for families and children may be a limitation when sensitive topics must be addressed.

Our study did not inquire about some of the positive aspects of TH in the delivery of care for child neurology patients. For example, there likely is a percentage of individuals who benefit from being home for their evaluations with neurologists, such as young children and those with significant anxiety. Moreover, in the setting of autism evaluations, despite the lack of

standardized, validated measures utilized on TH platforms, the home environment is more naturalistic for the patient who does not require a mask and other personal protective equipment as they would during an in-person evaluation.

Despite the above noted limitations, the strengths of this study are that this was a quick survey to implement and obtain real time feedback from clinicians. Importantly, it addressed specific areas that are imperative to clinical care in the setting of the global pandemic and can inform our future clinical practices. As the COVID-19 pandemic continues, and even after its resolution, we anticipate that TH will remain and/or become a significant part of most child neurology practices.

The following recommendations may be considered to improve future TH care for providers in child neurology:

- Practices may consider implementing a triage system for certain diagnoses and for children under 1 year of age.
- Reevaluate the minimum age for TH visits
- Child neurologists will benefit from additional training in the TH evaluation of specific conditions, notably neurodevelopmental disorders such as autism spectrum disorder and neuromuscular conditions which are less amenable to TH.
- Medical practices should continue to provide immediate and live technical assistance to providers working remotely and patients who experience technical difficulties.
- Medical practices should improve the use of translator services during TH visits to encourage providers to utilize this seamlessly and broaden the access to care.
- Focus groups of patients and providers may be able to identify ways to strengthen the healing relationship between patient and provider using TH.
- Training institutions may consider providing interns, residents, and fellows with specific training on the use of TH and the utilization of specific toolkits as they become available.
- All medical providers and healthcare systems should continue advocating for appropriate reimbursement of TH.
- All medical providers and healthcare systems should consider specific liabilities potentially posed by TH.
- Researchers should consider studying electronic medical records with coding and billing patterns to identify specific trends in payor groups and other groups to identify gaps in service delivery.

The worldwide pandemic and emergency implementation of TH has forced the practice of child neurology into the 21st century.<sup>21–30</sup> TH has many advantages over in-person care, including bringing comfort and treatment to those who have difficulty traveling to the practitioner's office because of physical disability, distance, or socio-economic isolation, or time constraints. TH has allowed the practice of child neurology to continue during the global pandemic; however, we must be aware of its limitations and while following the mission of

delivering compassionate, appropriate, and indiscriminate patient care.

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### Author Contributions

JMB contributed to conception and design, contributed to acquisition, analysis, and interpretation, and drafted the manuscript. SG contributed to conception and design, contributed to acquisition and interpretation, drafted manuscript, and critically revised the manuscript. SET and JS contributed to conception and design, contributed to acquisition, analysis, and interpretation, drafted manuscript, and critically revised the manuscript. MG contributed to conception and design, contributed to acquisition and interpretation, drafted manuscript, and critically revised the manuscript. WGS contributed to conception and design, contributed to acquisition and analysis, drafted manuscript, and critically revised the manuscript. CD contributed to conception, contributed to acquisition and analysis, critically revised manuscript. All the authors gave final approval and agrees to be accountable for all aspects of work ensuring integrity and accuracy.

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