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Pediatric Teleneurology in the Time of the Pandamic; Favourable Outcomes from Implementation of Telemedicine in Pedriatric Epilepsy and Autism Clinincs During the Covid-19 Pandemic

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Abstract

The COVID-19 pandemic incited the implementation of telemedicine throughout many pediatric neurology clinics, including our epilepsy and neurodevelopmental disabilities clinics. We performed a quality improvement study regarding physicians' and patients' experiences with telemedicine. Physicians and parents reported satisfaction with virtual visits with 96% of parents requesting continuation of telemedicine. Emergency room visits increased rarely for patients with epilepsy and autism-spectrum disorder (ASD). Many (85.8%) parents of children with ASD reported no/rare increase in concerns about ASD-related symptoms, and 94% of patients with epilepsy had no/rare increase in seizure frequency. At least 30% of patients with epilepsy reported favorable quality of life after the pandemic while patients with ASD struggled with socialization, seeking friendships, anxiety with changes, adherence to a routine, ritualized behavior patterns, and destructive behaviors after onset of the pandemic. Teleneurology can result in favorable outcomes for pediatric patients while reducing barriers encountered for in-person visits.

Keywords: teleneurology; virtual visit; QOLCE; QOLA; COVID-19 pandemic

Introduction

Telemedicine has been a means of providing pertinent healthcare in neurology for the past three decades.[1] The practice of telestroke emerged in the late 1990s, after alteplase was approved by the Food and Drug Administration (FDA) for the treatment of acute stroke, whereby neurologists provided treatment recommendations via telecommunication.[1] Research regarding delivery of stroke care via telemedicine has even proven it to be a cost saving measure. Seattle Children's Hospital and the University of Washington School of Medicine have been providing telemedicine in pediatric neurology to many states inclusive of Washington, Alaska, Montana, and Idaho with reported success.[2] Telemedicine has also been used in a subset of populations within pediatric neurology such as children with rare diseases like Batten Disease.[3]

Telemedicine can lead to similar health outcomes as compared to care provided in-person. A 2005 study revealed similar outcomes for seizure control, emergency visits and hospital admissions for epilepsy patients seen in-person and via telemedicine in Galveston, Texas.[4] A 2020 review, by the American Academy of Neurology (AAN) Telemedicine Work Group, showed that multiple subspecialties in neurology, including headache and concussion, epilepsy, neuromuscular, movement disorders, and dementia, achieved similar patient satisfaction and clinical assessments during telemedicine visits as compared to in-person visits.[5] Studies examining telemedicine diagnostic services involving observation of parental administration of parts of the Autism Diagnostic Observation Schedule-2 found high levels of agreement between the diagnostic outcomes of the televisits when compared to in-person visits.[6,7] There remains a need for future studies regarding patient satisfaction and quality of life.[4]

Telemedicine is especially beneficial for patients and their families who have limited access to healthcare, such as those who live far from hospitals and clinics or who have transportation challenges.[8] The underserved populations that face these challenges are more often from low socioeconomic backgrounds. A study completed at Vanderbilt University found positive yields in providing telemedicine to underserved populations.[8]

In Texas, the use of telemedicine expanded after the passage of the SB 1107 bill in 2017 that relaxed relatively stringent physical encounter requirements for telemedicine visits.[9] Changes included removing the requirement of a face-to-face consultation between a new patient and a physician.[9] During the COVID-19 pandemic, a sudden need arose to incorporate additional virtual visits into outpatient healthcare delivery. As a result of the suspension of certain regulations and implementation of emergency rules, the Texas Medical Board further expanded the use of telemedicine as a means of establishing a new physician-patient relationship and increased its use for diagnosis, ordering of tests, treatment, and prescribing for all conditions.[10]

When the COVID-19 pandemic began impacting in-person healthcare visits in March 2020, virtual visits were implemented in our pediatric neurology clinics to continue to provide our patients with access to quality medical care. Our study was part of a quality improvement initiative and was designed to investigate the landscape of pediatric neurology telemedicine in the early stages of the pandemic. This information can help researchers understand patients' and their parents' perspectives of this means of healthcare delivery. We believe that not only can virtual visits expand access to health care for patients in rural areas, but they can also result in health outcomes similar to in-person visits.

The primary objectives were 1) to clarify the benefits and challenges of telemedicine as perceived by pediatric neurologists, 2) to analyze patient-parent-provider interactions and satisfaction rates, 3) to study quality of life for patients in relation to virtual visits administered and the pandemic, and 4) to follow short-term health outcomes (interim emergency visits, breakthrough seizures and changes in autism spectrum disorder (ASD) symptoms).

Methods

Study Design

This was an observational retrospective study. The protocol was approved by the University of Texas Southwestern Medical Center Institutional Review Board (IRB) and Children's Health at Dallas as being IRB exempt. One component of the study focused on patients and their parents' experiences with virtual visits and the patients' quality of life and outcomes prior to and after the onset of the pandemic. Patients seen at the Children's Health at Dallas hospital system in Dallas, Texas, USA, for virtual visits from March 15, 2020 to August 30, 2020 were enrolled in the study. Inclusion criteria included previously established patients within the pediatric neurology department who had undergone virtual follow-up visits. Exclusion criteria were 1) new patient visits, 2) second opinion visits, 3) patients whose guardians had changed while establishing care with the pediatric neurology department because these guardians might not be fully aware of the patient's baseline health status to be able to compare long-term health progress or decline, and 4) patients who had not been seen in-person for more than 24 months prior to the virtual health visit.

The study team enrolled 101 consecutive patients primarily followed for epilepsy either at the Level 4 Epilepsy Center or General Neurology clinic, and 100 patients, who were primarily followed for ASD, from the Center for Autism and Developmental Disabilities in the same hospital system. Patients were enrolled in the study at least 6 months after their virtual visit. To facilitate chart reviews of enrolled patients, direct identifiers (medical record number) were maintained during data collection in a secure file. Subsequently, direct identifiers were removed and data were anonymized.

The second component of the study, completed simultaneously as patient component, focused on physicians' experiences during virtual visits. Any physician who had performed a virtual visit from March 15, 2020 to August 30, 2020 was eligible for participation in the study. Parents of patients and physicians were consented verbally prior to participation in the study.

Outcome Measures

Satisfaction surveys were administered to physicians and parents (of enrolled patients) who participated in the virtual visits. Answers were scored on a Likert scale from 1 to 5; a free-response section was also included. Quality of life measures included Quality of Life in Childhood Epilepsy-16 (QOLCE-16), a shortened version of the original measure, for patients followed for epilepsy and Part B of Quality of Life in Autism Questionnaire (QoLA) for patients followed for ASD.[11] Part B of QoLA consists of questions that are answered by caregivers to evaluate the severity of their child's ASD symptoms.[12] Parents reported their children's symptoms, using a Likert scale, prior to onset of the pandemic and shortly after the onset of the pandemic (both based on parental recall of the time periods). Additional measures, as reported by parents, included change in emergency room (ER) visits during the pandemic, ease of access to medication refills, baseline neurological health in the interim, change in frequency of breakthrough seizures, change in frequency of ASD symptoms (when applicable), and change in frequency of clinic calls.

Telemedicine Platform

The telemedicine platform used was provided by Amwell and approved by the Children's Health hospital system. The platform allowed for real-time video and audio communication between the physician and the patient/parent. Patients required cellular data or high speed internet access to participate in the telemedicine visits. All parents provided consent to complete telemedicine visits. The platform was not integrated into the electronic medical record. Physicians were able to complete a limited physical exam of the patient via the real-time video.

Statistical Analysis

Descriptive statistics was used to describe results from the physician satisfaction questionnaires, parent/patient satisfaction ques-

tionnaires, the healthcare outcomes, and the quality of life measures. For the physician questionnaire results, two-tailed t-tests were used to compare faculty and trainee responses. Wilcoxon signed-rank tests were performed on the pre- and post-pandemic QoLA Part B results for patients with ASD. Cohen's d, which is a standardized measure of mean differences, was used to analyze effect size of significant pre- and post-pandemic QoLA Part B results. Statistical analysis was performed using IBM SPSS Statistics Version 26.0. Statistical significance was set at a p-value of 0.05.

Physicians' Perspectives

Pediatric neurology attendings, fellows, and residents had similar levels of satisfaction in almost every metric assessed (Table 1). Overall, physicians had slightly favorable views towards virtual visits (Table 1). Physicians perceived decreasing the need for transportation as a significant benefit of telemedicine visits over in-person visits (Table 2). Physicians considered reduced travel challenges as a possible cause for decreasing no-show rates. Virtual visits allowed physicians to examine patients in a more natural setting and decreased patient anxiety (Table 1). Physicians also had greater flexibility in scheduling quick follow-up visits.

Attendings and trainees reported similar perspectives about the degree to which limitations in virtual visits altered management. Limitations of virtual visits only infrequently changed clinical management of patients, though physicians indicated that they commonly wanted to see patients in-person sooner due to these limitations (Table 1). The inability to perform a complete neurological exam was another drawback, but this rarely affected clinical management.

Most of the disadvantages were not centered on the modality of telemedicine itself. The key complications were network connectivity issues and patients and families having difficulties using the platform (Table 2). Physicians had difficulties adding other members of the health care team, such as language interpreters or other physicians, to the telemedicine visits. Additional shortcomings included the inability to show images via the telemedicine platform, lack of instructions in Spanish for patients to access the platform, and lack of integration of the platform into the electronic medical record.

Table 1: Physician perceptions of satisfaction and limitations of telehealth video visits, using Likert scale of 1 (almost never) to 5 (almost always).

	Faculty (n=24)	**Trainees (n=14)**	**p-value**
Satisfaction regarding:			
Ability to communicate easily with patients	3.67	3.79	0.66
Ability to get physical examination data necessary for clinical decision- making	3.33	3.36	0.93
Ability to document during the virtual visit	3.63	3.57	0.88
Ability to use language translation services	2.33	2.64	0.45
Ability to include trainees or faculty	2.57	3.15	0.09
Overall with telehealth visits	3.50	3.64	0.90
Limitations			
How often did limitations in telehealth change your medication and/or management for patients?	2.04	2.00	0.75
Did having a virtual visit make you schedule a sooner follow-up than if it were an in-person visit?	3.21	3.07	0.65

Table 2: Physician perceptions of the advantages and disadvantages of telehealth video visits over in-person visits

	Faculty (n=24)	Trainees (n=14)
Advantages		
Minimizing transportation challenges for patients and families	100%	100%
Being able to minimize anxiety levels of patients	67%	71%
Being able to communicate more efficiently	17%	36%
Being able to document more efficiently	29%	29%
Being able to schedule patient for quickerfollow-up	71%	71%
Disadvantages		
Connectivity issues	88%	79%
Difficulties in patients being able to use platform	71%	79%
Difficulties in physicians being able to use platform	17%	29%
Difficulties in doing physical exam	42%	50%
Difficulties in communicating effectively with patients	25%	14%

Telemedicine for Patients with Epilepsy

Participating patients had follow-up virtual visits in the beginning of the COVID-19 pandemic when the virtual application was initially implemented. The majority of parents reported that breakthrough seizures did not increase above baseline (15.8%) or rarely increased (78.2%) above baseline seizure frequency following virtual visits (Figure 1A). Participants reported no (42.6%) or rare (57%) change in visits to the ER (Figure 1B) after the implementation of telemedicine. The frequency of calls to the neurology clinic for concerns, questions, or medication refills minimally increased after virtual visits with 42.6% of parents reporting a rare increase in calls and 55.4% reporting no change in calls to clinic (Figure 1C). Medication compliance increased with 84.1% of parents reporting that their children were more compliant. In contrast, 11.9% of participants felt that their children were less compliant (4 participants did not respond).

Parents reported ease of communication with the physician during the virtual visit, with 98% of families indicating that communication was "very easy." No participants reported dissatisfaction with communicating with the physician virtually. All participants indicated that they understood the physician's advice very easily (Figure 1D). Nearly all participants (95%) preferred future visits to be virtual with 76.2% indicating that they would defer to the physician's recommendation for how often future visits should be virtual. Sixteen-point eight percent preferred every other visit to occur virtually, and 3% of families wanted all future visits conducted virtually.

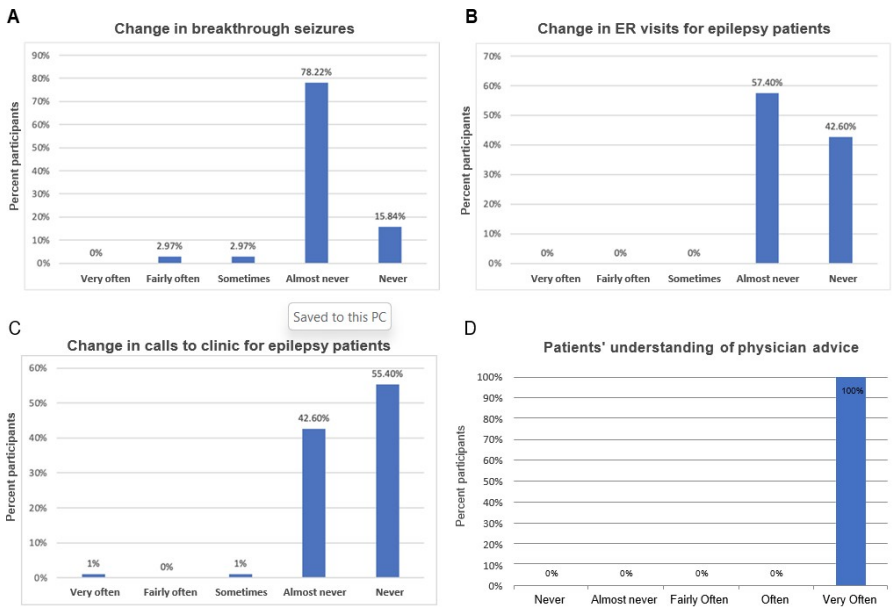

Figure 1: A) Change in number of breakthrough seizures after implementation of telemedicine visits. B) Change in emergency room (ER) visits after implementation of telemedicine visits. C) Change in number of calls for questions/ concerns to the epilepsy/neurology clinics after implementation of telemedicine visits. D) Frequency of parents re- garding how often they understood the physician's advice during telehealth visits.

To assess the quality of life for patients with epilepsy during the COVID-19 pandemic, the QOLCE-16 was administered. QOLCE-16 tested the four domains of cognitive, emotional, social and physical functions. Questions regarding the cognitive, emotional, and social domains were phrased such that patients who had more difficulties within those domains would respond with "often" or "very often".[11] However, for questions posed for the fourth domain of physical function, such as "how often has your child played freely in the house like other children his/her age," responses of "often" or "very often" specified favorable physical function.[11] In the setting of virtual visits and the pandemic, greater percentage of participants scored on the favorable side ("sometimes" to "never") of the spectrum in all of the domains (Figure 2). Nearly 30% of participants reported rare or no cognitive difficulties, and 40% of participants had rare or no emotional difficulties. Notably, 37.8% of participants indicated very favorable physical functioning.

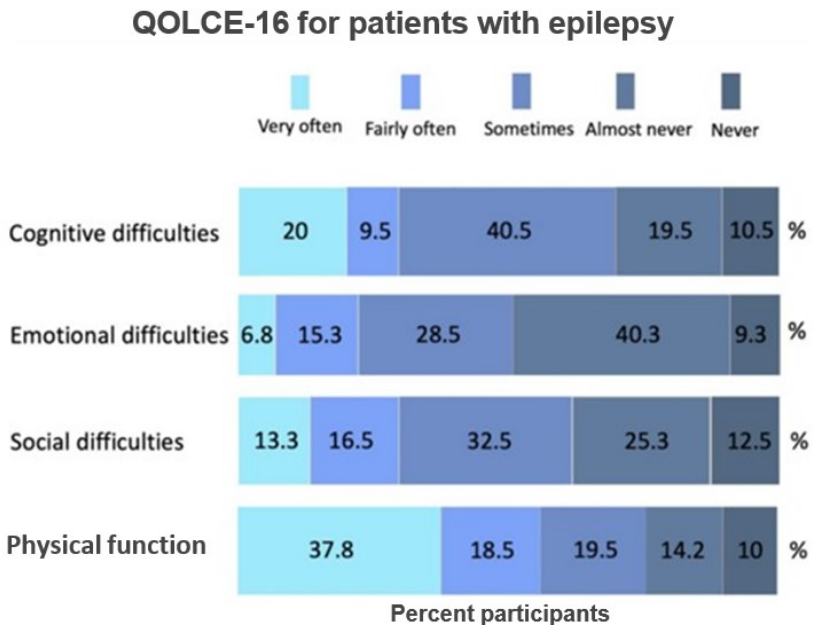

Figure 2: Responses to the QOLCE-16 (quality of life measure) for patients with epilepsy after onset of the COVID-19 pandemic. Responses of "very often" and "often" are favorable for the "physical function" domain.

Telemedicine for Patients with ASD

Many parents of children with ASD reported no change (58.6%) or only a rare increase (27.3%) in their concerns about their children's ASD behaviors, sleep, or social interactions (Figure 3A). None of the families felt the shift to virtual visits resulted in worsening behavior. Ninety eight percent of the parents reported never having to go to the ER for issues related to the child's ASD (Figure 3B). Favorably, 82% of families reported almost never or never calling the neurology clinic for questions/concerns after their virtual visits (Figure 3C).

The majority (89%) of the participants felt that there was no change in medication compliance. Four percent of parents felt their children were more compliant, and 7% felt their children were less compliant. This measure considered behavioral medications and any other medications prescribed for ASD-related issues. The majority of participants understood the physician's advice during virtual visits (Figure 3D). Most (91.92%) of the families wanted to continue telemedicine in the future with 28% preferring all future follow-ups to occur virtually.

We assessed the change in ASD symptoms pre-pandemic and after the onset of the pandemic using the QoLA Part B. Characteristics that significantly worsened with the onset of the pandemic included socialization, building friendships, need to adhere to a routine, anxiety in specific situations and with changes, ritualized behavior patterns, and destructive behaviors ($p < 0.05$ for all six characteristics) (Figure 4). Cohen's d indicated small effect sizes (0.2 – 0.324) for each of these ASD features. Parents reported that the root of the worsening behaviors were the changes resulting from the social isolation measures in place during the COVID-19 pandemic.

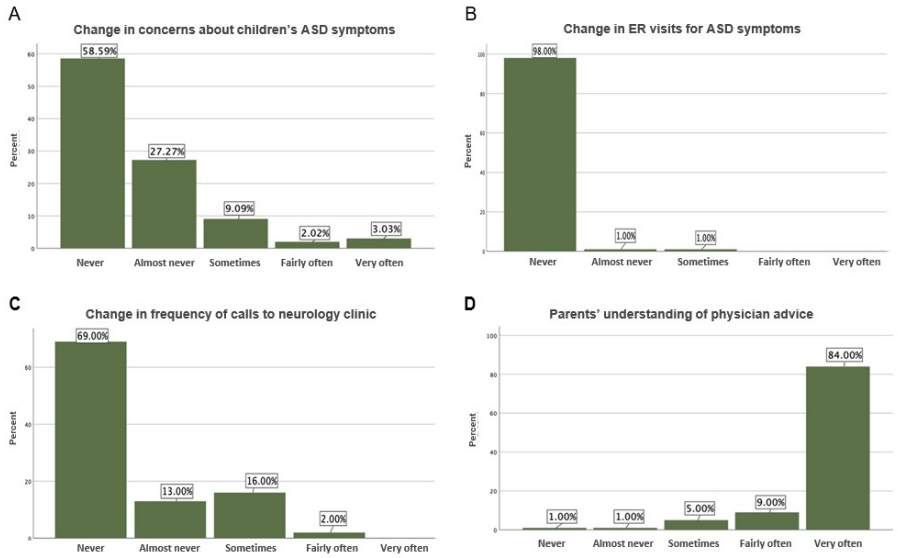

Figure 3: A) Change in parental concern about children's ASD symptoms after implementation of telehealth visits. B) Change in emergency room (ER) visits for ASD symptoms after implementation of telehealth visits. C) Change in number of calls for questions/concerns to the neurodevelopmental disabilities clinic after implementation of telehealth visits. D) Frequency of parents regarding how often they understood the physician's advice during telehealth visits. ASD - autism spectrum disorder

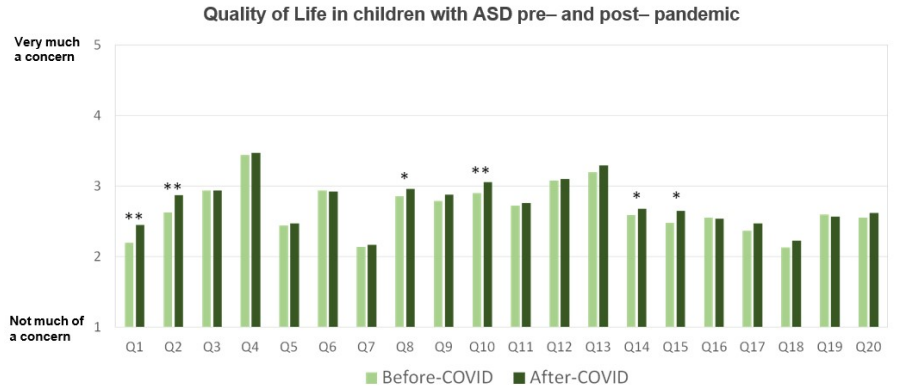

Figure 4: Parental responses to the Quality of Life in Autism (QoLA) questionnaire for children with ASD. Parents scored their pre- and post-pandemic impressions on a Likert scale with 1 as "not much of a concern" and 5 as "very much a concern." Behaviors that significantly changed after the pandemic are: * indicates $p < 0.05$ for Q8 (adhering to routine), Q14 (ritualized behavior patterns), and Q15 (destructive behaviors), and ** indicates $p < 0.01$ for Q1 (socialization), Q2 (seeking friendships), and Q10 (becoming anxious in specific situations or with changes). Q1 to Q20 represent the twenty questions of the QoLA. ASD - autism spectrum disorder

Discussion

Due to the COVID-19 pandemic, legislation allowed for increased insurance coverage and expanded services delivered via telemedicine. [11] The pandemic also paved the way for first-time implementation of telemedicine services in some departments, such as ours. In our Pediatric Neurology department, virtual visits were not available prior to the COVD-19 pandemic but were quickly implemented throughout multiple subspecialty clinics.

In this study, we investigated the characteristics of providing health care to pediatric neurology patients via telemedicine during the COVID-19 pandemic and examined telemedicine's potential in maintaining quality patient health outcomes and access to healthcare. Physicians had favorable views regarding communication with patients, documentation, and the ability to obtain data

necessary for clinical decision making. As anticipated, limitations in performing a complete neurological exam virtually did not hinder clinical management. It is noteworthy that these patients were expected to have a stable exam. Physicians also felt that virtual visits decreased no-show rates and allowed for greater flexibility in scheduling follow-up visits. Telemedicine visits have been associated with higher visit completion rates as determined by a study of general pediatric neurology telemedicine clinics of underserved patients [13]

Parents were highly satisfied with virtual visits and the ease of communication with physicians. It was clinically significant that no participants reported dissatisfaction with virtual communication with physicians. Parents of children with ASD emphasized how beneficial virtual visits were for their children because of the reduction in the stress of preparing their children for traveling and removal of transportation as a barrier for some families. Similar results were noted in previous studies of pediatric neurology telemedicine clinics [14,15] These benefits from telemedicine do not need to be limited to the circumstances of a pandemic. With improvement in the pandemic and return to typical life, including children returning to schools, virtual visits can prevent children from missing school and parents from missing work. Each family member can log into the visit from their respective locations, which actually occurred for a few virtual visits at our clinics.

Health outcomes, indicated by markers including breakthrough seizures, ER visits and calls to the clinic, were positive during the use of telemedicine visits. The majority of patients with epilepsy rarely had an increase in breakthrough seizures and rarely visited the ER. A study comparing in-person and telemedicine epilepsy clinics showed that both clinics had similar ER visit rates.[4] Another study comparing hospital encounters, including ER visits and hospital admissions, between cohorts attending telemedicine visits and in-person visits demonstrated that the telemedicine cohort had lower hospital encounter rates.[16]

Because of the COVID-19 pandemic, some families in our clinics were hesitant to come to the ER due to fear of contracting COVID-19. However, a truly significant worsening in baseline status following virtual visits, in conjunction with fear of coming to the ER, would have consequently resulted in an increase of calls and concerns to the neurology clinic. Instead, 98% of participants reported almost never or never changing their frequency of calls to the neurology clinic. The quality of life measures were also favorable with the minority of the participants reporting very frequent cognitive, social, emotional, and physical difficulties. This reinforces that telemedicine visits can lead to positive health outcomes while alleviating transportation and time barriers for patients.

The majority of parents of children with epilepsy reported increased anti-seizure medication compliance. While this is another positive outcome, there are confounding factors. Increasing medication compliance could be the result of improved effective communication through virtual visits but also a consequence of parents being able to more closely monitor medication administration because they were working from home during the pandemic. Another possible cause could be the fear of having to take their child to the ER during an ongoing pandemic, also resulting in stricter medication administration.

Parents of patients followed virtually for ASD also expressed satisfaction with virtual visits, and health outcomes were favorable for children with ASD. Similar to the patients followed for epilepsy, 99% of the participants reported never having to take their child to the ER. Considering families' hesitancy to come into the hospital during the pandemic, we did not see a consequent increase in calls to the neurology clinic following a virtual visit. Telemedicine can be a beneficial alternative to traditional visits without leading to a decline in patient outcomes. A recent systematic review of studies of autism assessments and interventions delivered via telemedicine revealed high parent satisfaction and treatment acceptability. [17]

During this study, we had sought to determine any resulting changes in quality of life for children with ASD after the implementation of telemedicine. With regard to ASD-related behaviors, such as sleep issues, stereotypies, and reciprocity and development, 85.86% of parents reported almost never and never seeing these behaviors worsen in their children after the initiation of virtual visits. This could be because virtual visits were effective, as supported by the high parental satisfaction rate. However, the lack of worsening behaviors was also seen in children whose parents were able to maintain a similar routine during the pandemic as prior to the pandemic as well as seen in those children who were able to restart therapies, at least virtually.

The pandemic itself had a substantial affect on children with ASD because routines were disrupted, therapies, such as Applied Behavioral Analysis, were halted, and children were socially isolated. All of these factors are necessary for children with ASD to progress.[18] Parents in our study indicated that six ASD-related behaviors significantly worsened (socializing with others, having friends/seeking interest in friendships, anxiety in specific situations and with changes, needing to adhere to a routine, ritualized behavior patterns, and destructive behaviors including anger and aggression) after the onset of the pandemic. These factors were heavily affected by the social isolation rules implemented due to the pandemic. Five percent of parents indicated that changes wrought by the pandemic resulted in worsening behaviors. This highlights the importance of continued assessment of quality of life in relationship to virtual visits after the pandemic improves to ascertain a more accurate picture of telemedicine's impact on children with ASD.

A recent study in Israel, in which parents answered a qualitative questionnaire during lockdown early in the pandemic, relayed parental concerns and anxiety about their children's challenges, including isolation in space and from peers, lack of a routine that was practiced at school, and upended family dynamics.[18] These findings resonated with parental comments in our study. A 2021 study of parents of children with autism in Quebec identified similar themes, and children who participated considered social isolation as an important factor contributing to their stress.[19] Parents identified several factors that led to improved coping during the pandemic. The factors considered most crucial were understanding their children's needs and establishing a new routine.[19] The parents in our study also expressed the importance of understanding children's needs and establishing a routine in order to help their children cope with the pandemic.

While implementation of telemedicine within our pediatric neurology clinics resulted in favorable health outcomes for our patients with epilepsy and ASD and was advantageous for parents, this study also revealed aspects that can be strengthened for future virtual visits. Connectivity issues posed the greatest challenge for physicians and more so for parents. Physicians were unable to show images, such as MRI brain or CT Head images, to parents via the platform and had difficulty adding interpreters and trainees to the visits. These limitations are potential targets for future quality improvement investigations to enhance the quality of telemedicine.

Our study was limited by the recruitment of patients who experienced the COVID-19 pandemic, thus introducing confounding factors such as fear of being in a hospital and unprecedented social isolation affecting quality of life. Parental responses to questionnaires about the satisfaction with virtual visits, quality of life and health outcome measures, were based on parental recall. This is another source of potential bias. Our cohort of patients was followed for epilepsy and ASD but not for the multitude of other neurology subspecialty conditions. These patients also experienced new implementation of virtual visits, but were not included in our study due to time limitations in surveying these families.

Conclusion

Telemedicine helped to fulfill a chasm in healthcare created by the COVID-19 pandemic and the consequent social isolation. Implementing virtual visits to increase health care access in the time of a pandemic was not just beneficial towards keeping patients safe but also reduced barriers that families encountered for in-person visits. Parents were highly satisfied after virtual follow-up visits because these visits saved time, decreased transportation costs, and minimized disruption of their children's routines. Health outcomes, as judged by ER visits and clinic calls, did not significantly increase after the transition to telemedicine. Our study provides support for the use of telemedicine as an alternative to or in association with traditional in-person follow-up care and support for further investigation towards improving telemedicine delivery. This valuable data is necessary to advocate for our patients, especially those who live remotely and would benefit from telemedicine. Avenues for future quality improvement projects for our virtual platform include incorporating the presentation of clinical images and integrating the video platform into the electronic medical record.

Author contributions

T.R.K. designed the study, collected, and analyzed the data, interpreted the results, wrote and edited the manuscript.

A.S. designed the study, collected, and analyzed the data, and interpreted the results.

P.R.C. collected and analyzed the data, interpreted the results, wrote and edited the manuscript.

M.J. reviewed and participated in editing the final manuscript.

R.S. designed and supervised the study and interpreted the results.

All the authors approved the final manuscript.

Conflict of Interest

The Authors declare that there is no conflict of interest.

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