Barriers, access and management of paediatric epilepsy with telehealth

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Abstract

Access to paediatric neurology care is complex, resulting in significant wait times and negative patient outcomes. The goal of the American Academy of Pediatrics National Coordinating Center for Epilepsy's project, Access Improvement and Management of Epilepsy with Telehealth (AIM-ET), was to identify access and management challenges in the deployment of telehealth technology. AIM-ET organised four paediatric neurology teams to partner with primary-care providers (PCP) and their multidisciplinary teams. Telehealth visits were conducted for paediatric epilepsy patients. A post-visit survey assessed access and satisfaction with the telehealth visit compared to an in-person visit. Pre/post surveys completed by PCPs and neurologists captured telehealth visit feasibility, functionality and provider satisfaction. A provider focus group assessed facilitators and barriers to telehealth. Sixty-one unique patients completed 75 telehealth visits. Paired t-test analysis demonstrated that telehealth enhanced access to epilepsy care. It reduced self-reported out-of-pocket costs ($p<0.001$), missed school hours ($p<0.001$) and missed work hours ($p<0.001$), with 94% equal parent/caregiver satisfaction. Focus groups indicated developing and maintaining partnerships, institutional infrastructure and education as facilitators and barriers to telehealth. Telehealth shortened travelling distance, reduced expenses and time missed from school and work. Further, it provides significant opportunity in an era when coronavirus disease 2019 limits in-person clinics.

Keywords

Introduction

Epilepsy, a common chronic neurological condition characterised by recurrent unprovoked seizures, impacts children's health and quality of life, along with that of their families.[1] Children and youth represent one of the fastest growing populations affected by epilepsy – the most common childhood neurological condition in the USA.[2] Negative effects on cognition and physical development, as well as social stigmatisation and poor quality of life, are commonly observed in children and youth with epilepsy (CYE). Furthermore, CYE are at higher risk for developmental, intellectual

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and mental-health co-morbidities, including attention-deficit/hyperactivity disorder (ADHD), autism, learning disabilities, depression and anxiety.[3–6]

Often, the evaluation of a child with seizures starts with a paediatrician in a primary-care practice or an emergency room. Children are then referred to a neurologist or epileptologist for further evaluation, family education and the development of a management plan. Unfortunately, treatment and referral patterns for CYE are not uniform or standardised across the country. While some CYE are treated by a paediatric neurologist or an epileptologist, many CYE, particularly those in rural and medically underserved areas, do not have access to specialty and coordinated care. A national shortage of paediatric neurologists and a primary-care workforce lacking in the requisite knowledge base and skill sets may exacerbate the difficulty in effectively diagnosing and managing epilepsy.[3] In regions where paediatric neurology care is not available, families travel for several hours from rural areas or wait weeks for clinic appointments.[7] In 2002, wait times for an appointment with a paediatric neurologist averaged 53 days for a new patient visit and 44 days for a follow-up visit, with longer wait times in university settings.[7] Diagnostic studies such as an electroencephalogram and neuroimaging studies, along with ongoing care, require additional travel, which is an added burden to the child (missing school) and parents (missing work). Access to specialty care can be further challenging in rural parts of the country where travel is especially difficult during times of inclement weather. Early access, prompt diagnosis and management has been shown to decrease seizure frequency and improve clinical outcomes.[1] Access barriers, such as an insufficient number of trained primary and subspecialty care health-care providers, may lead to adverse health outcomes due to lengthy wait times, with delays in diagnoses and intervention, increased family and child stress and anxiety and reliance on emergency room services.[8]

Telehealth, defined as, 'use of electronic information and telecommunications technologies to support and promote long-distance clinical health care, patient and professional health-related education, public health and health administration', is a digital solution in health care that can provide quality care, increase timely access, minimise travel distances and reduce costs.[8] Significant growth over the last two decades has allowed telehealth to reduce access challenges in resource-poor specialties such as paediatric neurology and to garner support by the American Academy of Neurology (AAN). The AAN telemedicine position statement supports the integration of telemedicine in all states, noting benefits in access, cost-efficiency and clinical effectiveness.[9] Studies from Canada and Argentina evaluating the use of telehealth for adult epilepsy care have provided insights with regards to costs and productivity in those countries, and an adult descriptive study portrayed the benefits of telehealth for patients at home.[10–12]

In March 2020, a critical new role for telehealth in the care of paediatric epilepsy became necessary, as the coronavirus disease 2019 (COVID-19) worldwide pandemic limited or halted in-person clinic visits. The use of telehealth became recommended as a standard of care in some situations in this setting, for example for infantile spasms.[13] However, a survey of paediatric caregivers showed that only 15% of paediatricians had used telehealth.[14]

The American Academy of Pediatrics (AAP) National Coordinating Center for Epilepsy has worked to test and establish a multifaceted system to ensure that CYE, particularly those in medically underserved and/or rural areas, have access to the medical, social and other supports and services required to achieve optimal health outcomes and improved quality of life. The Access Improvement and Management of Epilepsy with Telehealth (AIM-ET) project was designed by the Center to help alleviate barriers to health care for CYE. The objective of AIM-ET is to reduce wait times and improve access for patients/families by connecting them directly with a specialist to manage CYE and co-morbidities via telehealth.

Methods

In 2017, the AIM-ET project operationalised a small collaborative partnership with three paediatric neurology teams, representing three mutually exclusive underserved states, all of whom partnered with a local primary-care team consisting of a health-care provider, information technology staff and a nurse or medical assistant. One team included a partnership with the statewide Department of Public Health instead of a local primary-care team. Another of the initial partnerships' catchment area embraced two states. The original three partnerships collaborated over a 13-month period to implement and make improvements in their telehealth program for CYE. A fourth paediatric neurologist/primary-care provider (PCP) dyad, representing two more states, joined the pilot 11 months after the initial launch. These multidisciplinary dyad teams utilised quality improvement (QI) methodology, including the Model for Improvement and its Plan, Do, Study, Act cycles, to develop and implement telehealth in their states. A hub-and-spoke model of synchronous telehealth using live two-way videoconferencing was implemented to provide clinical care for the paediatric patient with epilepsy. AIM-ET utilised self-reported measures to operationalise access and visit satisfaction. Data were collected, analysed and shared with

Table 1. AIM-ET measures and projected improvement.

Similar or better satisfaction scores as in-person paediatric epilepsy/seizure disorder visits.

Similar or better provider satisfaction scores with telehealth visits for patients as in-person paediatric epilepsy/seizure disorder visits.

Similar or better paediatric neurologist satisfaction scores with telehealth visits for patients as in-person paediatric epilepsy/seizure disorder visits.

Reduction in family out-of-pocket costs (i.e. gas, lodging, tolls, parking, meals out, lost work time, childcare costs) with telehealth visits for epilepsy/seizure disorder visits.

10% reduction in appointment scheduling wait times with telehealth for established patients with epilepsy/seizure disorders.

20% reduction in missed school hours for epilepsy patients using telehealth visits.

20% reduction in missed work hours for parents of paediatric epilepsy/seizure patients using telehealth visits.

20% reduction in transportation mileage of families of paediatric epilepsy/seizure patients using telehealth.

AIM-ET: Access Improvement and Management of Epilepsy with Telehealth.

individual practices to facilitate access and management improvement (Table 1). Institutional Review Board (IRB) approval was obtained by the AAP and the individual agencies based on specific institution requirements.

The AIM-ET project team included a paediatric epileptologist who served as the Medical Director of the Center, Chair of the AAP Section on Telehealth Care, a telehealth consultant, a QI adviser and AAP staff. The expert group members had experience in telehealth implementation, prior paediatric epilepsy QI projects and advanced training in QI methodology.

Study design and population

The study design was a QI project implementing telehealth visits for CYE in ambulatory paediatric epilepsy clinics, with the aim of enhancing access and management. The telehealth visits were compared to in-person paediatric epilepsy care.

Four paediatric neurologists, all epileptologists and the primary-care practice collaboratively recruited CYE. Patient-specific inclusion criteria included: patients between 2 and 21 years of age, diagnosis of epilepsy and/or seizure disorder and willingness to complete a telehealth visit with their paediatric neurologist and having previously completed at least one in-person clinic visit. Patients having a first-time seizure or febrile seizures were excluded. For the purpose of this study, we defined telehealth visits as synchronous (live) audio and video sessions using a HIPPA-compliant and encrypted platform chosen by each neurologist/PCP dyad at their respective originating sites.

Post-telehealth visit surveys, designed to compare access measures in the telehealth visit and the in-person neurology visit, were evaluated for face validity. All parents/caregivers were asked to complete a survey electronically either in SurveyMonkey or in print format. Each dyad, paediatric neurologist/PCP team, designated a person to enter their monthly project data for the team using a custom chart review tool. Microsoft Excel was used to collect and analyse all data. The QI expert analysed the data and distributed measure-specific graphs to each practice at an individual (practice) and aggregate level on a monthly basis. These periodic summaries illustrated the impact of telehealth integration efforts at each site in addition to conference calls with the QI expert to discuss project challenges and best practices.

Each lead PCP and paediatric neurologist completed a pre/post survey regarding comfort, knowledge and ease of use and functionality of telehealth in the office setting. The survey provided a way to identify changes undertaken to incorporate telehealth successfully in the office setting.

The AIM-ET initiative provided services to 61 unique CYE, completing 75 telehealth visits. All of the patients had an in-person visit with their neurologist prior to the telehealth visit. Although all geographic sites were able to integrate telehealth visits, only data from three sites were used for analysis. IRB approval for the fourth site was not completed within the project time frame.

Evaluation

Statistical analyses were performed on all individual questions from the patient post telehealth survey and the physician pre/post survey. Demographic data include counts, percentile and rank. A two-sample paired t-test with the significance of $p < 0.05$ was used for the same group comparisons for all access measures. A summary of practice characteristics and the ways in which local environments impacted the integration of telehealth visits are presented in Table 2. To capture lessons learned and successes within the unique health-care systems, an external evaluator conducted post-project focus groups with three of the sites (Alabama – University of Alabama at Birmingham/ Alabama Department of Public Health (ADPH), California – Stanford University and Utah/Idaho – University of Utah/Pocatello, Idaho) in early 2019.

Table 2. Practice characteristics.

	Alabama	California	Missouri/Kansas	Utah/Idaho
Practice partnership	Sole level 4 paediatric epilepsy programme in Alabama, Children's Hospital of Alabama in Birmingham, partnered with the Alabama Department of Public Health (ADPH) which has a health department clinic in each of the 65 Alabama counties.	Stanford Pediatric Epilepsy Group partnered with a general affiliated paediatrics practice located in Monterey. Paediatric subspecialists from Stanford had intermittently travelled to this site to offer outreach clinic, providing a pre-existing infrastructure, including a shared electronic medical record (EMR) and contracts in place for financial logistics.	Some of the barriers that arose included clarifying whether this was research (and as such required Institutional Review Board (IRB) approval) or quality improvement (IRB exempt), creating a contract between the paediatric practice and Children's Mercy Kansas City (CMKC) and finding the supporting staff trained to perform a neurological exam at the paediatric practice.	The University of Utah paediatric neurology practice at Primary Children's Hospital in Salt Lake City, Utah, partnered with Pocatello Children's Clinic. Pocatello Children's Clinic is an underserved region of Idaho. A University of Utah paediatric neurologist travelled to this clinic 8–10 clinic days per year, but additional patient visits remained in high demand.
IRB process	IRB approval was obtained from both the University of Alabama and ADPH.	IRB required and obtained from both sites. The telehealth post-visit survey initially approved was amended to align with the other project practices and required an IRB amendment.		IRB approval was not required or sought at the Utah or Idaho sites.
Geographical reach	Telehealth services occurred in six counties, increasing at the end of the project period to 14 counties.	Primary-care provider (PCP) practice was 90 miles south of Stanford children's epilepsy centre.		Telehealth services occurred at the PCP 164 miles away from the Utah neurology centre. The Utah neurology centre covers a large catchment area, including five neighbouring states, servicing approximately two million children.
Patient selection process	Patients residing in or near the available counties were selected at their in-person epilepsy visits. All patients were routinely followed by the project epileptologist. Patients initially selected for study participation tended to be older children with normal neurodevelopment and seizures that were relatively well	Telehealth visits were offered as follow-up visits to patients older than one year of age who had previously been seen by a Stanford paediatric neurologist within the past three years. As only one Stanford paediatric neurologist participated, if patients had previously seen a different provider in the group, they were given the option of		Recruitment of patients was an initial challenge, which was primarily attributed to a lack of awareness and being unfamiliar with this method of health delivery. Recruitment improved after advertising flyers were placed in the clinic and education about the project was increased for patients,

(continued)

Table 2. Continued.

	Alabama	California	Missouri/Kansas	Utah/Idaho
	controlled. As the comfort level of all the staff increased, more complex patients were included in the roster.	trying a telemedicine visit with the AIM-ET paediatric neurologist. The PCP queried their EMR for any patient with an ICD-9 diagnosis of 345.x (epilepsy), with a report generated monthly to identify newly eligible patients. Those who were already under care with a Stanford epileptologist or neurologist were offered the option of a telemedicine follow up visit in place of an in-person follow-up at Stanford. A project coordinator reached out to the families of these patients to offer telemedicine visits in place of in-person appointments.		families, clinicians and schedulers.
Telehealth visit workflow	The telehealth visit was scheduled by an administrative assistant. Families checked in at the county health clinic where vital signs were obtained. Any lab orders, medication instructions and refills were either sent by mail or prescribed via the EMR.	Appointments were scheduled by the epilepsy centre coordinator and offered based on availability of the paediatric neurologist and the telemedicine equipment at the Stanford site. On the day of the visit, families checked in at the originating site front desk. The paediatric neurologist was paged and notified of arrival; the medical assistant (MA) collected vitals and roomed the patient, and made the telehealth connection before leaving. The paediatric neurologist ran the visit and ended the visit remotely upon appointment completion. Prescriptions, information and any other instructions were sent to the family via the EMR messaging portal.		The patient visit was scheduled by schedulers at the Utah neurology site. Families checked in at the PCP site in Pocatello, Idaho, and were roomed by a MA; vital signs were obtained, and the Utah epileptologist was notified when the patient was ready via the chat function on the Vidyo Telehealth platform. The MA connected the patient and distributed the post-telehealth visit survey. After-visit medical summaries were printed by the MA in the clinic or were mailed to the patient.

(continued)

Table 2. Continued.

	Alabama	California	Missouri/Kansas	Utah/Idaho
Education and resources	Educational materials, including handouts and video on paediatric epilepsy, were formulated. Counties were strategically selected, and educational materials were reviewed by staff from the corresponding county health clinic. County health clinics were equipped with scales and paediatric blood pressure cuffs for obtaining vital signs. Initial staff training around paediatric epilepsy was required.	Recruitment to the telehealth clinic included advertising with clinic flyers and personalised invitation from the neurologist or schedulers based on study inclusion criteria and home address.		A printed advertisement flyer was placed in all Utah neurology clinic waiting rooms.

Results

The final analysis included a total of 61 unique participants. Participants ranged from 1.5 to 18 years old and were predominantly white (76%), with co-morbidities including developmental disabilities (24%), ADHD (10%), depression or anxiety (9%) and cerebral palsy (8%). See Table 3 for patient demographics.

Access measures (i.e. patient missed school hours, parent missed work hours, out-of-pocket expenses and miles travelled) all presented statistically significant improvements with telehealth compared to in-person visits (Table 4). Patient satisfaction (97%) and physician satisfaction (100%) with telehealth visits documented the overall improvement with telehealth. Measurement of missed school hours was reduced with telehealth by 49% ($p < 0.0001$) and missed work hours by 48% ($p < 0.0001$). Statistical significance ($p < 0.0001$) was also found with miles travelled and self-reported out-of-pocket expenses: telehealth visit mileage (32 miles) compared to an in-person visit mileage (49 miles) and out-of-pocket expenses for telehealth (US$35) compared to out-of-pocket expenses for in-person visits (US$176). Wait times for an appointment were indirectly analysed using a five-point Likert scale looking at 'ease of getting an appointment when wanted' (Table 4). Getting a telehealth appointment was identified by parents/caregivers to be easier, with 95% strongly agreeing/agreeing, compared to 65% of those receiving in-person appointments strongly agreeing/agreeing. Overall, CYE experiencing telehealth visits were generally satisfied and reported better access when compared to those receiving in-person epilepsy visits.

Teams provided anecdotal observations regarding facilitators and barriers to telehealth through individual focus groups (Table 5). Unique barriers that arose and impacted integration of telehealth included clarifying whether this was research (and as such required IRB approval) or quality improvement (IRB exempt), creating a contract between the paediatric practices and specialty sites and finding the supporting staff trained to perform a neurological exam at the paediatric practice. It has also been critical in building a relationship between the neurology and PCP teams, opening the way to more ambitious projects. Pre-project telemedicine certification of all seven epilepsy centre epileptologists and their willingness to participate in telehealth shortened the timeline, further supporting access. In the Utah/Idaho dyad, poor audio quality improved with the purchase of a separate microphone for the PCP office. Excess background noise from siblings or young, active patients improved with tablet distraction offered at the visit, and wireless Internet connection problems improved with a dedicated visit room near

Table 3. Telehealth visit characteristics: aggregate and for specific geographical sites.

		Aggregate (%), N = 61	Alabama (%), n	California (%), n	Utah/Idaho (%), n
Age	Range		2–18 years	5–13 years	1.5–18 years
	Average		10 years 7 months		9 years 0 months
Race	African American	9	29	0	0
	Hispanic	12	4	100 (white Hispanic)	11
	Multiracial	3	8	0	89
	White	76	58		0
Co-morbidities	Attention-deficit/hyperactivity disorder	10	21		9
	Cerebral palsy	8	8	25	9
	Developmental delay	24	37.5		27
	Mental health	9	8	25	12
Seizure type	Absence	10	8	0	12
	Focal	28	29	25	27
	Generalised	28	21	50	27
	Specific syndrome	31	42	25	27
	No response		0	0	6
Seizure control	No seizures	45	42	50	47
	Daily	17	21	0	17
	Weekly	12	8	0	15
	Monthly	13	29	25	4
	No response	12	0	25	17
Treatment	No medication	3	4	0	2
	1 medication	49	37.5	50	28
	>1 medication	39	58	25	57
	Diet (ketogenic)	4	4	0	4
	No response	8	0	25	9
Duration of medication	<6 months	23	8	0	30
	6–12 months	13	8	0	13
	12–24 months	8	4	25	6
	2–5 years	24	25	25	13
	>5 years	17	54	25	19
	No response	15		25	0

a router. Recruitment of patients was an initial challenge which was primarily attributed to a lack of awareness and unfamiliarity with this method of health-care delivery. Recruitment improved after advertising flyers were placed in clinic and education was increased about the project for patients, families, clinicians and schedulers.

Discussion

Data from this study illustrate the important role of telehealth in reducing the perceived family burden and decreasing out-of-pocket expenses related to medical visits, school and work and miles travelled without diminishing parent/caregiver satisfaction. Participation in the AIM-ET project supported local practices with their adoption of telehealth to provide greater access to high-quality epilepsy care. The AIM-ET model can be easily replicated to guide other practices to integrate telehealth, especially in underserved and rural locations.

In recent weeks, a wide range of telehealth models have been adopted, including in-home telehealth visits, which may add convenience and further cost savings. While this type of remote access is necessitated by the current environment, the AIM-ET model using a local clinic as an originating site has some unique advantages. First and foremost, it enables visual assessments of the patient by a health-care provider, which may be important in assessing subtle seizures or medication side effects for example. Unique to the paediatric population is weight-based dosing of anti-seizure medications. AIM-ET enables procurement of vital signs which may be needed for paediatric dosage adjustment.

The other advantage of AIM-ET is its inherent adaptability to suit 'local' needs while performing standardised care and ensuring the safety of patient health information. It was adapted by three academic centres in three states across the USA, resulting in

Table 4. Patient survey results.

Measure	Visit type	n	M	SD	df	t-stat	t-critical, one-tailed	p-Value	Decision
Missed work hours	In person	64	3.82	0.244	126	−6.244	1.657	<0.0001	Significant
	Telehealth	64	1.83	0.204					
Missed school hours	In person	63	3.92	0.226	124	−6.323	1.657	<0.0001	Significant
	Telehealth	63	1.95	0.211					
Out-of-pocket expenses	In person	74	$176	16.998	146	8.235	1.655	<0.0001	Significant
	Telehealth	74	$35	4.219					
Mileage to visit	In person	72	49	0.776	142	−7.408	1.655	<0.0001	
Telehealth	Significant	72	32	2.265					

$\alpha = 0.05.$

AIM-ET measure	Telehealth	Easy to get appointment when wanted? In person	Easy to get appointment when wanted? Telehealth
Visit scheduled when wanted	n = 64	Strongly agree: 24 (38%) Agree: 17 (27%) Neutral: 14 (23%) Disagree: 5 (8%) Strongly disagree: 2 (3%)	Strongly agree: 40 (63%) Agree: 20 (32%) Neutral: 9 (14%) Disagree: 0 (0%) Strongly disagree: 0 (0%)
Patient satisfaction	n = 68	More satisfied with telehealth: 7 (10%) Equally satisfied with telehealth: 59 (87%) Less satisfied with telehealth: 2 (3%) AIM-ET goal equally or more satisfied with telehealth: n = 66 (97%)	

operationalised telehealth practices, each with a distinct set-up and infrastructure. With its primary-care partner practice in Idaho, the project in Utah provided telehealth services across state lines. The project in Alabama partnered with ADPH which has initiated the development of a state-wide network of care, with the goal of equipping each of the 67 counties with the training and equipment to set up epilepsy follow-up clinics. The arm in California provided access to tertiary care for a relatively rural community with a predominantly Latino population. Despite these differences in local populations and the communities served, telehealth services were successfully deployed, achieving a common goal of providing easier access to care for CYE. Each site was able to identify common themes among lessons learned and future implications: systems, patient engagement and the provider teams.

Learnings from the AIM-ET model underscore that building telehealth infrastructure requires administrative support, programme staff, financial resources and technical support. Working closely with the paediatric neurologists at the hub/medical centre sites and the local PCPs at the spoke sites is critical to the successful implementation of telehealth technology. In particular, early identification of provider relationships, infrastructure development and education and programme promotion can be critical to develop strategies for these essential elements. Socialising both providers and patients, as well as identifying a champion in advance, can help ease adoption. Sharing lessons learned and ways to facilitate adoption of this new medical delivery system are also beneficial. Payment, the regulatory landscape and licensing of physicians and other health-care providers that are cumbersome to navigate need to be further addressed to keep up with the rapid changes in the health-care landscape.

Our project had several limitations. The initial delays encountered in establishing this project across sites resulted in a small sample size. The post-telehealth survey was also limited in scope, validity, reliability and the one-to-one comparison of telehealth to in-person visits. Questions to reflect better the extent of miles travelled/saved by very rural remote patients, the safety of travel during inclement weather, quality of life especially for parents who are not working or with children not in school, and enhanced questions to measure if a patient is seen sooner through telehealth versus a traditional clinic visit along with a more robust data set would provide better assessment. Additional measures such as standardised epilepsy measures, costs and technological effectiveness can be used to gauge successful delivery of health care. This will help add clarity and optimise telehealth models to improve access, efficiency, as well as clinical and team effectiveness and cost. The National Quality Forum has created a framework for measuring telehealth which could further guide measurement selection.[15]

Table 5. Focus group–identified facilitators and barriers to telehealth adoption.

Key challenges	Verbatim barriers	Facilitators
Developing and maintaining partnerships	Different medical electronic systems make everything a little challenging. For example, our group is the only one that can do the scheduling. The PCP cannot do the scheduling. They have to direct patients to call our scheduling group. The PCP office usually emails me and they tell me that a patient wants to be seen via telehealth visits and I will take it from there. Another problem is that the PCP side has only 'reading access' to our system. I order labs, but I order them in our system. As long as I have very good communication with the MAs at the PCP sites, they are able to do the labs that I need there, and they are able to print out education material that I want to give to patients, such as a visit summary and a seizure action plan. So, they can do all that, but they cannot document vital signs. So, I had to learn how to do that myself and document them.	Human factors – namely flexibility and tenacity – particularly when faced with shifting programme requirements, were paramount to progress and achievements.
A lack of institutional infrastructure to support telehealth visits also presented challenges	…there's no common site or a place where somebody can come to do telehealth visits … the technology's only on individual laptops, at least for epilepsy for me. That is going to be a glitch as this programme grows, and it goes beyond one provider. We would need more physical space or at least a designated space to conduct telehealth visits. There are certain sites where the signal goes off every now and then, so you can't carry on a smooth conversation with patient families.	A lot of hustle on [team member's] part to be quite honest. As things would get changed mid-project or when we had the IRB shutdown for example, a lot of time was put in, often with no or very short notice, to do whatever was needed to get things back up and running or meet whatever the new requirement was. That's the way we did it. The first six months, we were very flexible. We had two clinics per month, and if a patient wanted to be seen outside of those clinics, I was open to do that [location] and offering it in person or the PCP's office, occasionally offering it in-person to a family …we're still struggling, I would argue, with how to actually let [families] know. We also printed up an advertisement flyer to put in all of our clinic offices here so if someone is sitting in the waiting room they could say, 'Oh there's tele-neurology between [location] and [location]? That's cool'.
The amount of education and promotion required to support office staff and generate interest in telehealth visits among families of children and youth with epilepsy	Another issue is recruitment for telehealth and advertising the service … we had to come up with a flyer to talk to our schedulers about it because they weren't really familiar with it … If parents asked questions, [schedulers] didn't have the details. We came up with an info sheet for them, and I think that helped, but it's still really more came down to identifying patients from [location] and offering it in person or	

Table 5. Continued.

Key challenges	Verbatim barriers	Facilitators
	the PCP's office, occasionally offering it in-person to a family . . . we're still struggling, I would argue, with how to actually let [families] know. We also printed up an advertisement flyer to put in all of our clinic offices here so if someone is sitting in the waiting room they could say, 'Oh there's tele-neurology between [location] and [location]? That's cool'.	
	We were initially selecting patients and actively calling to make this opportunity known. Then we realised that it's too much work on our side, but I think it was really helpful for the beginning. So, we decided to change the way we do things. The next step was we just selected all the patients with seizures seen in our clinic in the last six months and sent the list to the schedulers to call all of them.	

With the worldwide COVID-19 pandemic of 2020, telehealth has become widely adopted for use. In the first two months of the COVID-19 pandemic, many states in the USA temporarily ceased state-specific licensing requirements for the provision of telehealth. Our data suggest that for patients and families, this adoption will provide benefits in saving of time and cost. However, particularly for patients and families who receive their care in regions geographically remote from a specialist, state licensing restrictions as well as insurance restrictions may pose significant barriers. For example, for a patient and family who might have to travel several hundred miles to see a paediatric epileptologist, telehealth would provide significant potential savings. However, now states are again requiring state-specific licenses (https://www.healthit.gov/faq/are-there-state-licensing-issues-related-telehealth), and Medicare and other insurance companies often have restrictive or limited payments for telehealth.[16]

In future studies, it will be interesting to compare different telehealth platforms, including for ease of use, satisfaction of providers and patients, reliability and ultimately patient outcomes. Difference in the platforms could lead to variability in access and user experience. Interestingly, however, our outcomes were similar at different sites, despite use of different platforms, suggesting that the software platform is less important than the overall opportunity for varying clinical settings and different state regulations.

Conclusions

Our results show that telehealth can be successfully implemented and adapted by private, public and academic centres in various combinations for follow-up paediatric epilepsy care. Future studies of telehealth will be necessary to delineate short- and long-term effects on outcomes, and on limitations and solutions of licensing and payment models. Telehealth technologies can provide greater access for health-care services, with potential savings for patients and the health-care system. The AIM-ET model also provides a significant opportunity to complement in-person care and supplement ongoing management in an era when COVID-19 further limits in-person visits for this population.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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