# Telehealth for patients with rare epilepsies

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# Abstract

Recent developments in technology and exigencies of the COVID-19 pandemic have spurred innovations for telehealth in patients with rare epilepsies. This review details the many ways telehealth may be used in the diagnosis and management of rare, pharmacoresistant epilepsy and documents our experience as measured by surveying caregivers of pediatric patients with epilepsy. Most components of the epilepsy evaluation, including history and examination, neuroimaging, and electroencephalogram (EEG) can be performed or reviewed remotely, assuming similar technique and quality of diagnostic studies. Seizure and epilepsy diagnosis is enhanced through the assistance of caregiver smart phone video recordings and 'ambulatory' EEG. Monitoring patient seizure frequency through paper seizure diaries is now increasingly being replaced by electronic diaries in both clinical and research settings. Electronic seizure diaries have numerous advantages such as data durability, increased accessibility, real-time availability, and easier analysis. Telehealth enhances access to specialized epilepsy care, which has been shown to reduce mortality and improve patient compliance and outcomes. Telehealth can also enable evaluation of patients with rare epilepsy in centers of excellence and enhance enrollment in clinical trials. Reducing mortality risk in patients with epilepsy can be accomplished through remote counseling and addressing psychiatric co-morbidities. Findings from surveying caregivers of children with epilepsy treated at Children's National Hospital showed that 54/56 (96.4%) found that not having to commute to the appointment positively contributed to their telemedicine experience. Overall, most respondents had a positive experience with their telemedicine visit. Almost all respondents (98%) were either very happy' or 'happy' with their telemedicine visit and their ability to communicate over telemedicine with the provider and either 'very likely' or 'likely' to want to use telemedicine for some future clinic visits. Telehealth in rare epilepsies is feasible and, in many ways, comparable with traditional evaluation and management.

# Plain Language Summary

# Telehealth for patients with rare epilepsies

Recent technological advancements and constraints caused by the COVID-19 pandemic have spurred innovations for telehealth in patients with rare epilepsies. This review details the many ways telehealth may be used in the diagnosis and management of rare, drug-resistant epilepsy and documents our experience as measured by surveying caregivers of pediatric patients with epilepsy. Most components of the epilepsy evaluation can be performed or reviewed remotely, assuming similar technique and quality of diagnostic studies. Seizure and epilepsy diagnosis is enhanced through the assistance of caregiver smart phone video recordings and 'ambulatory' electroencephalogram (EEG). Monitoring patient seizure frequency through paper seizure diaries is now increasingly being replaced by electronic diaries in both clinical and research settings. Ther Adv Rare Dis

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Keywords: child neurology, rare epilepsy, telehealth, telemedicine

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#### Introduction

Epilepsy afflicts more than 65 million people worldwide and 3.4 million people in the United States, including approximately 3 million adults and 470,000 children.<sup>1,2</sup> In fact, 1 in 26 people in the United States will develop epilepsy at some point in their lifetime.<sup>3,4</sup> While most patients respond adequately to treatment, approximately one-third are pharmacoresistant or 'refractory'.5 Genetic factors likely account for a substantial portion of these drug-resistant cases and those with unknown etiology. Overall, estimated annual incidence of rare, single-gene epilepsies identified on multi-gene panels is approximately 1 in 2000 live births.6 The most common genes account for the majority of these cases identified on epilepsy gene panels - PRRT2, SCN1A, KCNQ2, SLC2A1, CDKL5, PCDH19, DEPDC5, SLC6A1, KCNQ3, CACNA1A, STXBP1, STX1B, SCN8A, SCN2A, MECP2, UBE3A, TSC2, and GABRG2.<sup>6,7</sup> Many more have rare forms of epilepsy with unknown, but presumed genetic, cause.

Recent developments in technology and exigencies of the COVID-19 pandemic have spurred innovations for telehealth in patients with rare epilepsies that have improved access, patient safety, caregiver and patient satisfaction, and patient care without sacrificing quality. This review details the many ways telehealth may be used in the management of rare, drug-resistant epilepsy for diagnosis, evaluation, management, and counseling, and documents our experience as measured by caregiver survey in patients with epilepsy.

#### Diagnosis

Seizure diagnosis and classification is foundational to epilepsy management. Properly identifying and labeling seizures according to standard definitions enables epilepsy classification (focal, generalized, combined focal and generalized, unknown) and epilepsy syndrome diagnosis.<sup>8,9</sup> While there is substantial genetic heterogeneity in most presumed genetic refractory epilepsies, some have a strikingly characteristic phenotype implicating a specific gene (e.g. *SCN1A* in Dravet syndrome). Telehealth may be more feasible for diagnosis of certain epilepsy types. For instance, childhood absence epilepsy can be effectively diagnosed remotely, when necessary, and treatment initiated prior to electroencephalogram (EEG).<sup>10</sup>

The wide availability of smartphones with video capability has made video recording of seizures and non-epileptic events more commonplace. While video electroencephalogram (vEEG) remains the gold standard for diagnosis, smartphone video is often much simpler, more cost-effective, and timelier in guiding treatment decisions and is frequently accomplished through telehealth. There are a variety of methods by which caregivers can share videos with their medical team remotely. Expert review of these videos is highly accurate for distinguishing epileptic seizures and psychogenic non-epileptic attacks.<sup>11</sup> However, diagnosing other types of nonepileptic events such as movement disorders, common in many genetic epilepsies, *via* review of smartphone video may not be as reliable.<sup>11</sup> Regardless, remote smartphone video interpretation can be a useful adjunct to history and vEEG.

# **Evaluation**

The evaluation of patients with epilepsy begins with history and physical examination. There are certain components of the physical and neurological examination which are not possible remotely or are, at least, more challenging remotely. Most vital signs (including head circumference), auscultation of heart and lungs, fundoscopy, Wood's lamp skin examination, abdominal palpation for organomegaly, deep tendon reflexes, primitive reflexes, and tone are commonly performed in patients with rare epilepsy, but not feasible by telemedicine. However, other features of neurological examination via telemedicine (mental status, most cranial nerve assessments, various motor tasks, cerebellar function, Romberg, gait, and skin exam) may be comparable with in-person examination.<sup>12,13</sup> Laboratory evaluation such as medication levels and monitoring for adverse effects are often more easily accomplished during in-person visits. Compliance with recommended laboratory tests ordered via telehealth may suffer accordingly. However, using local labs and coordinating with other in-person visits can help. Furthermore, the telemedicine examination may perform similarly to in-person examination of uncooperative patients where much of the examination is based on observation alone.14 Uncooperative patients comprise a large proportion of rare epilepsy patients.

Standard evaluation for epilepsy includes neuroimaging and EEG. Magnetic resonance imaging (MRI) brain is preferred for epilepsy evaluation. However, the diagnostic yield can vary widely depending on variability in technique and expertise.<sup>15</sup> The International League Against Epilepsy (ILAE) recommends use of the Harmonized Neuroimaging of Epilepsy Structural Sequences (HARNESS-MRI) protocol, a minimum set of MRI basic sequences available on most MR scanners.<sup>16</sup> These include isotropic millimetric 3D T1 and FLAIR images, and high-resolution 2D submillimetric T2 images, a protocol optimized for detection of focal cortical dysplasias. Most recommended epilepsy protocol MRI include a standard thin-slice T1-weighted gradientrecalled-echo, axial and coronal T2-weighted fast spin-echo or turbo spine-echo, axial and coronal FLAIR, 3D T1-weighted volume acquisition sequences, and oblique coronal T2-weighted imaging of the hippocampus.<sup>17</sup> Children less than 2 years warrant high-resolution axial, coronal, and sagittal T1- and T2-weighted sequences. This epilepsy imaging protocol should be utilized at seizure diagnosis. Most MRI brain for early life epilepsies (age of onset < 3 years old) include axial and coronal T2-weighted sequence, axial and coronal fluid-attenuation inversion recovery sequence, high-resolution oblique coronal T2-weighted imaging of the hippocampus, anatomic, thin-slice volumetric T1-weighted gradient echo sequence, and maximal slice thickness not exceeding 5 mm (between 1 mm for T1 threedimensional images and 5mm for some T2-acquired sequences).<sup>18</sup> While repeat neuroimaging over time may be useful in patients with ongoing seizures despite appropriate therapy and in patients whose first image was before 24-30 months while myelination evident on MRI is still incomplete, ensuring quality MRI is collected after the first seizure can prevent unnecessary repeat neuroimaging. Referral centers must have easy and reliable access to these images.

EEG is a critical component of epilepsy management and aids in determining epilepsy type (focal versus generalized), epilepsy syndrome, and prognosis after new-onset unprovoked seizures.19 Subsequently, EEG is commonly employed to properly diagnose spells, distinguish epileptic seizures from non-epileptic events, characterize and diagnose seizure types, assess EEG background activity, record seizure frequency, detect interictal epileptiform abnormalities, aid in seizure localization for patients undergoing pre-surgical evaluation, and diagnose electrographic status epilepticus of sleep. Traditionally, continuous vEEG is recorded in the epilepsy monitoring unit; however, 'ambulatory' EEG has been increasingly used for this subpopulation. Ambulatory EEG is placed in the office or at home, then continued from overnight to several days in the home environment. Data are typically downloaded and transmitted to the neurophysiologist for asynchronous interpretation after the EEG is removed. Good candidates for ambulatory EEG may include patients with spells of indeterminate cause requiring ictal EEG to diagnose, patients in whom recording seizures without need for medication taper may aid in treatment decisions, or those undergoing evaluation for electrographic status epilepticus of sleep.<sup>20</sup>

It follows that ease of data transfer is another key component to effective telehealth. At Children's National Hospital, we provide expert remote pediatric EEG interpretation for several other hospitals in the region. Review of raw video and EEG data aids epilepsy specialists in seizure and epilepsy classification. The same holds for neuroimaging. Currently, these data are often stored and transmitted using digital media. However, cloud-based solutions may allow for more rapid and reliable data sharing. These are increasingly used for clinical and research applications.

Recognizing co-morbidities is another important aspect of epilepsy evaluation. In fact, screening for depression and anxiety is one of the American Academy of Neurology epilepsy quality metrics intended to improve care delivery.<sup>21</sup> A potential limitation of telemedicine is less opportunity to observe behavior than in an office setting. This can be mitigated by ensuring the child remains present for as much of the video visit as possible and specifically querying for behavior problems, mood disorders, and suicidal thoughts or behavior. A variety of screening tools may be administered remotely including the Patient Health Ouestionnaire (PHO-2 and PHO-9) and Generalized Anxiety Disorder-2 or 7 scales, while other cognitive and developmental tests are only validated for in-person assessment.<sup>22</sup> The ability to see a child in their home environment may actually offer an advantage in assessing problem behaviors if a child is more inclined to behave naturally at home.

# Management

Monitoring seizure frequency and response to medications guides treatment decisions. Electronic seizure diaries capturing data on seizure type, frequency, duration, and response to therapies can be shared remotely. Traditional paper seizure diaries are increasingly being replaced by these electronic diaries in both clinical and research settings. Electronic seizure diaries have a number of advantages - data are durable, easily accessible, available in real time, can be graphed for visual display, and some can be exported to the patient's electronic medical record.23 These electronic diaries can be shared with providers remotely or providers may be granted access to their patient's data. There are potential barriers including caregiver and patient comfort with a digital platform, associated cost (in some cases), increased setup time, and privacy concerns. Some platforms may also not be wellsuited to patients with rare epilepsies, as many such patients experience frequent seizures of different types. These diaries may also allow users to track medications, adverse effects, and seizure triggers. Epilepsy Foundation website details some common seizure diaries.24

Seizure action plans are another important part of epilepsy patient management, especially for patients with rare diseases who may have nonstandard acute seizure management protocols and for those seen remotely at a distant referral center with emergency care delivered closer to home. For instance, patients with Dravet syndrome should avoid sodium channel-blocking medications, as these may exacerbate seizures and status epilepticus.<sup>25</sup> Patients with mitochondrial disease should typically avoid medication that impair mitochondrial function like valproic acid, particularly with POLG-related disorders. In some cases, we list these medications as allergies to ensure they are not given. At other times, it may be more appropriate to provide the patient/caregivers with an emergency letter which can be given to emergency personnel or emergency department staff.

Access to highly specialized multi-disciplinary teams is a clear advantage to use of telehealth. At Children's National Hospital, we have several subspecialty epilepsy clinics that pair epileptologists with neuroradiologists, geneticists, nurse practitioners, physician assistants, dieticians, genetic counselors, psychologists, and neuropsychologists. Telehealth enhances access to specialized epilepsy care.<sup>26</sup> This specialized epilepsy care improves patient compliance and outcomes and reduces mortality.<sup>27,28</sup> Some multi-disciplinary programs not available at all centers, such as dietary therapies for epilepsy, are especially well-suited to telehealth.<sup>29</sup> Monitoring the efficacy and tolerability of the modified Atkins diet administered via telehealth is similar to in-person management.<sup>30</sup>

Telehealth can also enable evaluation of patients with rare epilepsy in centers of excellence and enhance enrollment in clinical trials particularly for underserved populations, consistent with the basic principle of justice central in the Belmont report.

The COVID-19 pandemic poses unique challenges to patients with rare forms of epilepsy, many accompanied by neurodevelopmental disability. While epilepsy does not inherently increase the risk for catching SARS-CoV-2 or developing more severe symptoms from an infection, some associated high-risk medical conditions, such as pulmonary disease, may.<sup>31</sup> Medications including corticosteroids, everolimus, and other immunemodulating drugs may cause immunosuppression. Furthermore, people with developmental disabilities may not be able to comply with safety measures such as social distancing and masking depending on their cognitive and behavioral function. Reducing exposure risk through telehealth mitigates risks of COVID-19.

In surveys of caregivers and patients receiving care through telemedicine, respondents indicate they feel supported by the team, satisfied with their epilepsy management, and receive clear information and counseling.<sup>26,32</sup> In addition, they note less lost time at work and school, lower travel time and cost, better access to medication, and more regular follow-up. Most patients with refractory genetic epilepsy have intellectual disability and related medical needs, motor impairment, and behavior challenges which make travel to an in-person visit more difficult. Telehealth can help to ease these additional travel burdens and allows the medical team to see home living conditions. Caregiver concerns exist over privacy and ease of use of digital platforms. Providers perceive obstacles in infrastructure support and remuneration and limitations in clinical examination.33

Patient and caregiver concerns exist over privacy and ease of use of digital platforms. Providers perceive obstacles in infrastructure support, remuneration, and limitations in clinical examination.<sup>33</sup> However, many features of neurological examination *via* telemedicine may be comparable with inperson examination.<sup>12,13</sup> Furthermore, telemedicine examinations may function similarly to in-person examinations of uncooperative patients where much of the examination is based on observation alone.<sup>14</sup> Uncooperative patients comprise a large proportion of rare epilepsy patients. Outcomes for telehealth are similar to in-person visits. There is class I evidence that seizure frequency is no different in patients with epilepsy undergoing telephonic consultation (mean time 10 min) *versus* those receiving standard face-to-face follow-up.<sup>34</sup> Another group's retrospective analysis of a telemedicine seizure clinic found that two-thirds were either seizure-free or improved by the last encounter.<sup>35</sup> They used telemedicine for a variety of epilepsy types and discussed surgical therapeutic options in one-third of the visits, demonstrating that telehealth is generalizable across multiple types of epilepsy surgery.

# **Education and counseling**

The importance of counseling hardly needs to be stressed for an audience interested in rare pediatric disorders. We routinely provide anticipatory guidance to such patients. However, patients with rare epilepsies warrant special attention to counseling on seizure precautions, acute seizure management, potential medication side effects, and sudden unexpected death in epilepsy (SUDEP). This education and counseling, which improves quality of life in patients with epilepsy, can be easily accomplished through telemedicine, often by a nurse experienced in epilepsy.<sup>36,37</sup>

Caregivers should be counseled on seizure triggers and avoidance when possible. Medication noncompliance is a common precipitant of status epilepticus and increases SUDEP risk.<sup>38,39</sup> Acute seizures are often distressing. Clinicians must equip caregivers with a clear understanding of how to respond: ensure patients are in a safe location, do not restrain a patient or place anything in the mouth, keep the airway open, time the seizure, and call for emergency medical services or administer rescue medication as indicated.

Reducing mortality risk in patients with epilepsy can also be accomplished through remote counseling and addressing psychiatric co-morbidities. People with epilepsy have a much higher risk of overall mortality, with standardized mortality ratios ranging between 2 and 4 times that of an age- and sex-matched standard population.<sup>40</sup> Many of these deaths are from external causes such as non-vehicle accidents (e.g. drownings) and suicide.<sup>41</sup> Comorbid psychiatric disorders are a major risk factor in these deaths. Education on seizure precautions – no bathing or swimming

| Table 1. | Demographic | characteristics | of survey | respondents. |
|----------|-------------|-----------------|-----------|--------------|
|----------|-------------|-----------------|-----------|--------------|

| Table 1. Demographic characteristics of survey respondents.    |                      |  |  |
|--|----------------------|--|--|
| Characteristic   | n (%)                |  |  |
| Number of respondents  | 56 (100%)            |  |  |
| Age of child   |                      |  |  |
| 0–4  | 6 (10.7%)            |  |  |
| 5–8  | 12 (21.4%)           |  |  |
| 9–12   | 14 (25%)             |  |  |
| 13–16  | 11 (19.6%)           |  |  |
| 17–20  | 9 (16.1%)            |  |  |
| 21–25  | 4 (7.2%)             |  |  |
| What is your primary location of care?                         |                      |  |  |
| Washington, DC   | 25 (44.6)            |  |  |
| Virginia   | 30 (53.6%)           |  |  |
| Maryland   | 1 (1.8%)             |  |  |
| How far is your commute to your location of care?              |                      |  |  |
| 20 min or less   | 22 (39.2%)           |  |  |
| 30–60 min  | 30 (53.6%)           |  |  |
| >60 min  | 4 (7.2%)             |  |  |
| Does your child require medical equipment?                     |                      |  |  |
| Yes  | 14 (25%)             |  |  |
| No   | 42 (75%)             |  |  |
| Do you view your child as having a compromised im              | mune system?         |  |  |
| Yes  | 19 (33.9%)           |  |  |
| No   | 37 (66.1%)           |  |  |
| Do you view your child as having behavioral challen<br>visits? | ges during in-person |  |  |
| Yes  | 14 (25%)             |  |  |
|  |                      |  |  |

without appropriate supervision, avoiding heights, and generally avoiding situations where a seizure could result in serious injury – must be provided to patients and caregivers at diagnosis and periodically thereafter.

42 (75%)

More attention needs to be paid to educating people with epilepsy and their caregivers on

SUDEP as upward of 90% of this population wants SUDEP education but less than 15% receive it.<sup>42,43</sup> For most people with epilepsy, the risk for SUDEP is low. Approximately 1/1000 adults and 1/100044-1/450045 children with epilepsy succumb each year. Education should focus on modifiable risk factors - reducing seizure frequency, especially generalized tonic-clonic seizures, promoting medication compliance, and monitoring for seizures.<sup>39,45,46</sup> Children with 'complicated' epilepsy, meaning they have associated neurodisability or underlying brain condition, are at higher risk, about 1/1000 per person-year, but can be as high as 1/100 per person-year for adults with epilepsy and uncontrolled generalized tonic-clonic seizures.47 The most common form of rare genetic epilepsy, Dravet Syndrome, also has the highest risk of SUDEP. One in five individuals diagnosed with Dravet Syndrome will die prematurely, primarily as a result of SUDEP and usually at a young age.48,49

#### Our experience - survey data

We aimed to evaluate the benefits and challenges of telemedicine visits in relation to in-person office visits for caregivers of patients with epilepsy. To this end, we conducted a survey of caregivers of patients with epilepsy seen in the refractory epilepsy clinics of two authors (J.M.S. and W.D.G.) from July 2020 to September 2020. A family therapist with expertise in epilepsy (C.B.) conducted the interviews independently without the participation of the patient's epileptologist. This study was unfunded and deemed exempt by the Children's National Hospital Institutional Review Board because of the research design. Data collected included no personally identifiable information. Survey questions are included in Supplemental material.

There was a total of 56 respondents (Table 1). Patients' mean age was 11.5 years (standard deviation  $\pm$  5.9 years) at the time of survey (range, 2 months–25 years old). Respondents were normally seen for in-person care at Children's National Hospital clinic locations in Fairfax, Virginia (54%) or Washington, DC (40%), with one respondent typically receiving in-person care at the Rockville, Maryland, location. Twenty-two (40%) endorsed a typical commute to clinic of less than 20 min, 30 (53%) to 30–60 min, and 4 (7%) over 60 min. Despite these relatively brief commutes for

No

Table 2. Positive and negative contributing factors to telemedicine experience.

| Contributing factors  |           | No<br>n (%) | N/A<br>n (%) |  |
|---|-----------|-------------|--------------|--|
| Did the following reasons contribute to a positive telemedicine experience?                 |           |             |              |  |
| No commute  |           | 0           | 2 (3.6)      |  |
| No parking issues   |           | 1 (1.8)     | 3 (5.4)      |  |
| Reduced time out of school and work   | 52 (92.8) | 0           | 4 (7.2)      |  |
| Ability to focus on sensitive medical information without your child in the room            |           | 0           | 44 (87.6)    |  |
| No child care   | 21 (37.5) | 0           | 35 (62.5)    |  |
| Reduced challenges related to traveling with a child with special needs                     | 22 (39.3) | 0           | 34 (60.7)    |  |
| Improved timeliness   |           | 0           | 3 (5.4)      |  |
| Did the following reasons contribute to a negative telemedicine experie                     | nce?      |             |              |  |
| Challenges with technology  |           | 53 (94.6)   | 0            |  |
| Access to technology  |           | 56 (100)    | 0            |  |
| Distraction in the home   | 4 (7.2)   | 52 (92.8)   | 0            |  |
| Limited physical examination of your child  | 17 (30.3) | 38 (67.8)   | 1 (1.8)      |  |
| Limited personal experience   | 7 (12.6)  | 49          | 0            |  |
| Communication of instructions or understanding of recommendations                           | 2 (3.6)   | 54          | 0            |  |
| Added difficulty in coordinating and scheduling recommended tests, procedures, or referrals | 6 (10.8)  | 44          | 6 (10.8)     |  |

specialized epilepsy care, 54 (96%) of respondents reported that not having to commute to the appointment positively contributed to their telemedicine experience. In addition, more than 92% of all respondents reported that improved timeliness of the appointment, no parking challenges, and reduced time out of work and school all positively contributed to their telemedicine experience. Less than half of respondents felt that ability to focus on sensitive medical information without their child present (21%), no child care issues (37%), and reduced challenges related to traveling with a child with special needs (39%) contributed to a positive telemedicine experience. No respondents had issues with accessing technology necessary for telemedicine visits; however, a small proportion (5%) did have challenges with using the technology. The majority of respondents did not have issues with distractions in their home

(93%), limited personal experience (88%), understanding recommendations (97%), or additional difficulties coordinating and scheduling epilepsy management appointments (78%), which have the potential to contribute negatively to the telemedicine experience. Some did have concerns over limited physical examination, with 17 (30%) noting this as a negative aspect of the telemedicine visit (Table 2).

Overall, most respondents had a positive experience with their telemedicine visit. Almost all respondents (98%) were either 'very happy' or 'happy' with their telemedicine visit and their ability to communicate over telemedicine with the provider. Similarly, almost all respondents (98%) are either 'very likely' or 'likely' to want to use telemedicine for some future clinic visits (Table 3).

#### Table 3. Overall telemedicine experience.

| Questions                                       | n (%)      |  |
|---|------------|--|
| How happy are you with your telemedicine visit? |            |  |
| Very happy                                      | 43 (76.8%) |  |
| Нарру   | 12 (21.4%) |  |
| Neutral   | 1 (1.8%)   |  |
| Unhappy   | 0          |  |
| Very unhappy                                    | 0          |  |

How happy are you with the ability to communicate over telemedicine?

| Very happy   | 46 (82.1%) |
|--------------|------------|
| Нарру        | 9 (16.1%)  |
| Neutral      | 1 (1.8%)   |
| Unhappy      | 0          |
| Very unhappy | 0          |

What is the likelihood that you would want to use telemedicine for some future visits?

| Very likely   | 47 (83.9%) |
|---------------|------------|
| Likely        | 8 (14.3%)  |
| Neutral       | 0          |
| Unlikely      | 0          |
| Very unlikely | 1 (1.8%)   |

## **Future directions**

Telehealth in rare epilepsies is feasible and, in many ways, comparable with traditional evaluation and management. Many key aspects of epilepsy care, including seizure history, review of smartphone video, EEG and neuroimaging, and medical management can be performed remotely. There are several advantages to telehealth, mainly in reducing health risks and burden to families and in improving access to specialized epilepsy care with resultant better outcomes.

Additional study is needed into the validity of history and examination obtained through telemedicine and to identify potential gaps that might be addressed through changes in practice or technology, such as the utilization of wearable technology.

Institutions must adopt standards recommended for neuroimaging and EEG in patients with epilepsy. Guidance on the use of telehealth in epilepsy should be developed to aid in proper patient selection, evaluation, and management strategies. Technology employed should be easily accessible and intuitive, ensure high-quality video and audio connection (where applicable), maintain privacy and data security, and be capable of functioning at low bandwidth. Finally, changes to infrastructure and policy are critical so that telehealth remains viable. Payment parity with fair reimbursement will help motivate organizations and medical providers to support telehealth services where appropriate. Correspondingly, institutions should allocate resources for telehealth in order to better support providers and patients, especially when it comes to coordination of care and education after the telemedicine visit. Increasing availability of high-speed Internet is crucial, particularly because the people with the least access to specialized care also tend to have the least access to a reliable Internet connection. Revising laws regarding telehealth and state licensure for medical providers would allow for patients with rare epilepsies to see providers with expertise in these conditions. Telehealth is poised to occupy a primary role in rare epilepsy care, driving improvements in access, quality, cost, satisfaction, outcomes, and equity.

#### Author contributions

**Zachary J. Kramer:** Conceptualization; Formal analysis; Investigation; Writing – original draft; Writing – review & editing.

**Carrin Brandt:** Conceptualization; Data curation; Formal analysis; Writing – review & editing.

**Kathryn Havens:** Conceptualization; Data curation; Formal analysis; Writing – review & editing.

**Archana Pasupuleti:** Conceptualization; Data curation; Methodology; Writing – review & editing.

**William D. Gaillard:** Conceptualization; Investigation; Methodology; Writing – review & editing.

**John M. Schreiber:** Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Writing – original draft; Writing – review & editing.

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

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#### **Ethics statement**

This study was unfunded and deemed exempt by the Children's National Hospital Institutional Review Board (IRB #14275) because of the research design.

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Supplemental material

Supplemental material for this article is available online.

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