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## Ambulatory care for epilepsy via telemedicine during the COVID-19 pandemic



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### ABSTRACT

**Objective:** To assess feasibility, patient satisfaction, and financial advantages of telemedicine for epilepsy ambulatory care during the current COVID-19 pandemic.

**Methods:** The demographic and clinical characteristics of all consecutive patients evaluated via telemedicine at a level 4 epilepsy center between March 20 and April 20, 2020 were obtained retrospectively from electronic medical records. A telephone survey to assess patient satisfaction and preferences was conducted within one month following the initial visit.

**Results:** Among 223 telehealth patients, 85.7% used both synchronous audio and video technology. During the visits, 39% of patients had their anticonvulsants adjusted while 18.8% and 11.2% were referred to laboratory/diagnostic testing and specialty consults, respectively. In a post-visit survey, the highest degree of satisfaction with care was expressed by 76.9% of patients. The degree of satisfaction tended to increase the further a patient lived from the clinic ( $p = 0.05$ ). Beyond the pandemic, 89% of patients reported a preference for continuing telemedicine if their epilepsy symptoms remained stable, while only 44.4% chose telemedicine should their symptoms worsen. Inclement weather and lack of transportation were factors favoring continued use of telemedicine. An estimated cost saving to patient attributed to telemedicine was  $\$30.20 \pm 3.8$  per visit.

**Significance:** Our findings suggest that epilepsy care via telemedicine provided high satisfaction and economic benefit, without compromising patients' quality of care, thereby supporting the use of virtual care during current and future epidemiological fallouts. Beyond the current pandemic, patients with stable seizure symptoms may prefer to use telemedicine for their epilepsy care.

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### 1. Introduction

The ongoing COVID-19 pandemic has posed unprecedented challenges to healthcare across the world. The rapid surge in the number of SARS-CoV2-affected cases at the beginning of the pandemic created competing demands for hospitals [1], necessitating deployment of major resources for acute care while continuing to provide treatment for established patients with chronic debilitating conditions, such as epilepsy. Telemedicine services have been

recognized as an effective way to provide care during epidemiological and natural disasters [2–7]. Continued access to epilepsy care away from healthcare facilities was recommended by expert consensus to limit community spread of the SARS-CoV2 virus and is currently included in the guidelines by the Center for Disease Control and Prevention (CDC) [8,9].

In the United States, the Centers for Medicare and Medicaid Services (CMS) responded to the urgent demand for telemedicine and adjusted reimbursement guidelines [10]. This led to the rapid expansion of in-home telemedicine services across the country. While such a prompt response has opened the door to improve access to care for patients with chronic neurological disorders, it also introduced many logistical and technological challenges [11–15]. Recent reports have highlighted specific obstacles in the

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implementation of telemedicine services in neurology during the COVID-19 pandemic for adult and pediatric patients in both large metropolitan communities and rural areas [16–19]. Challenges included the lack of dedicated infrastructure, requirement for additional training for both patients and healthcare professionals in telemedicine technologies, inability to complete a comprehensive neurological exam, and apprehension of providers connecting with new patients indirectly through the camera lens [20]. In recent years, there have been several studies on telemedicine for epilepsy care [21–28]; however, the implementation of these subspecialty services in the United States during the COVID-19 pandemic has not been previously assessed.

The University of Nebraska Medical Center (UNMC) is one of three level-4 epilepsy centers serving the states of Nebraska, Iowa, and South Dakota where the population of patients with active epilepsy exceeds 59,000 [29]. In the present study, we summarize the experience of delivering ambulatory epilepsy care during the early months of the COVID-19 pandemic at our center. Specifically, we assessed the feasibility of this approach, economic and clinical care metrics, as well as patients' satisfaction related to these services. To our knowledge, this is the first study to examine patient-reported experience and care metrics for in-home telemedicine services during the COVID-19 pandemic specific to epilepsy.

## 2. Methods

### 2.1. Participants

This study was approved by the Institutional Review Board at the UNMC as a part of a quality improvement project. Telehealth services directly to patients' homes or nursing facilities were introduced at UNMC on March 15, 2020. The institutional telehealth team established capabilities (Zoom embedded in the Epic® electronic healthcare system) allowing the direct and secure access to virtual encounters from patient electronic medical charts, which could be accomplished via smartphone, laptop, or a tablet device. Clinic coordinators contacted the patients prior to their upcoming appointments to provide instructions via telephone or through a secure patient portal. Patients who had no access to devices other than a phone or had difficulties establishing an internet connection, were offered telephone (audio only) visits. The documentation of the telemedicine visits was performed using the template adapted from our traditional telehealth services.

This study included all consecutive new and returning adult and pediatric patients, five years and older assessed during tele-video or telephone encounters at UNMC by five board-certified epileptologists and two epilepsy advanced practice providers (APP) during the initial implementation of the home telemedicine services in response to the COVID-19 pandemic between March 20 and April 20, 2020. The providers spent 45–60 min on new visits and 25–30 min on return visits. All new patients referred to the epilepsy clinic and evaluated using the telehealth format were included in the study regardless of the specific seizure or spell history and the reason for a consult.

### 2.2. Data extraction and telephone survey

Retrospective chart review and analysis were conducted to extract the demographic and clinical characteristics of patients, including age, sex, epilepsy diagnosis, and number of antiepileptic drugs (AEDs). To assess the effectiveness of telemedicine visits, interventions like the number of medication changes, referrals to the epilepsy monitoring unit (EMU), diagnostic tests ordered, and specialist referrals made during the visit were recorded. Zip codes for the primary residence of each patient were identified to deter-

mine geodetic distance from the epilepsy clinic and cost savings related to reduced travel.

A brief six-question telephone survey was conducted with the participant's permission by an epilepsy clinic nurse case manager within one month of the initial telemedicine encounter. A total of three attempts were made to contact the patient or their surrogate. The survey was drafted in collaboration with an epilepsy neuropsychologist (Supplemental Data). Questions were aimed to assess patients' prior experience with using video call technologies, convenience of accessing the online patient portal for their telehealth visits, overall patient satisfaction, and the likelihood of retaining the telemedicine format for their visits in the future. The answer choices were provided on a Likert scale (Supplemental Data). We also asked patients were about factors that would influence their choice of telemedicine vs. an in-person visit.

### 2.3. Data analysis

The distance between a patient's residence and clinic was estimated by calculating the geodetic distance in miles (mi) between the centroid of a patient's home zip code and the centroid of the clinic's zip code. The gas cost saving was estimated using an average gas mileage of 30 mi/gallon and gas price of \$2.00. The time cost related to travel from the distance between patient's residence and clinic was estimated using an average speed of 30 mi/h and Nebraska's average hourly salary of \$17.00 [30]. The potential savings from parking and waiting time in the clinic for in-person visits were not considered in the current cost saving estimation.

Descriptive statistics were presented as frequencies or medians and interquartile ranges (IQRs). The associations between the responses to the survey questions and variables of interest (i.e., age, distance to clinic, and length of visit) were examined using Spearman correlations. The differences in the distribution of non-categorical variables of interest between dichotomous variable groups were examined using Wilcoxon Rank Sum tests. All analyses were performed using SAS software 9.4 (SAS Institute Inc., Cary, NC). Patient zip-code data were utilized to generate an interpolated, predictive surface map using inverse distance weighting to help visualize the approximate geographic distribution of patients utilizing telemedicine using ArcGIS Pro 2.6.1 (Esri, Redlands, CA).

### 2.4. Data availability

The data not included in the manuscript can be made available upon request.

## 3. Results

### 3.1. Patient demographic and clinical characteristics

Of the 265 patients who received telemedicine care at our center from seven epilepsy care providers during the study period, 34 were excluded as they were evaluated for conditions other than epilepsy. Eight additional patients did not meet the inclusion criteria (Fig. 1). A total of 223 patients were included in the study (Fig. 1).

The median age of patients at the time of visit was 35 years (IQR:26–49; Table 1). Ninety-one patients (40.8%) were male, and the rest were female. The majority of patients (85.7%) completed their encounters using a tele-video platform while the remaining 14.4% were converted to a telephone visit due to various technical difficulties or lack of access or familiarity to synchronous video technology. Sixty-six patients (29.6%) were new while 157 (70.4%) were return patients to our epilepsy clinic.

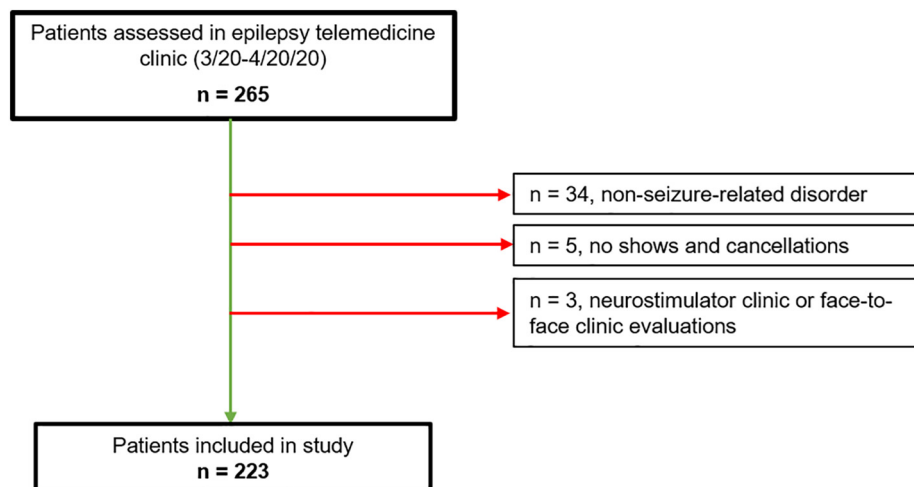


Fig. 1. Patient inclusion and exclusion criteria.

Table 1

Demographic and clinical characteristics of patients assessed during telemedicine visits. <sup>a</sup> Median and interquartile range; PNES, psychogenic nonepileptic spells; AED, antiepileptic drug; EMU, epilepsy monitoring unit. <sup>b</sup> Mixed: co-morbid PNES and epilepsy.

Patient characteristics	Number of patients (%)
Age, years (IQR) <sup>a</sup>	35 (26–49)
Sex	
Male	91 (40.8)
Female	132 (59.2)
Telemedicine visit type	
Tele video visit	191 (85.7)
Telephone visit	32 (14.4)
Epilepsy type	
Focal	120 (53.8)
Generalized	37 (16.6)
Unclassified	55 (24.7)
PNES	5 (2.2)
Mixed <sup>b</sup>	6 (2.7)
Usage of AEDs	
None	15 (6.7)
Monotherapy	70 (31.4)
Two agents	72 (32.3)
Three or more agents	66 (29.6)

More than one-half of the patients (53.8%) assessed during the telemedicine encounters had a diagnosis of focal epilepsy, while 16.6% suffered from generalized epilepsy, and 24.7% had poorly characterized or unclassified epilepsy (Table 1). Five patients (2.2%) had psychogenic nonepileptic spells (PNES), and six patients (2.7%) were treated for epilepsy with comorbid PNES. At the time of the telemedicine visit, nearly one-third of the patients (31.4%) were treated with a single anticonvulsant while 29.6% were medically refractory and were receiving three or more AEDs (Table 1).

The seizure burden was assessed in 205 (91.9%) patients who had the documentation of their seizure frequency in the electronic medical charts. Among them, 124 (60.5%) had been seizure-free in the three months prior to their telemedicine encounter; 66 (32.2%) patients reported more than one seizure per month; and the remaining 15 (7.3%) reported at least one, but no more than six seizures in the past year.

The no show rate for appointments scheduled during March–April, 2020, was 17%. This was similar to a 16% no show rate during the same time period in the previous year when all patients were seen in-person.

### 3.2. Diagnostic and therapeutic interventions

To improve patient seizure control and alleviate adverse effects of anticonvulsants, among 223 patients, 86 (38.6%) had an adjustment of their AED regimen (Table 2). Of note, 12 patients (5.4%) reported various side effects of anti-seizure medications, 58 patients (26%) found their existing drug regimens ineffective, and 16 patients (7.2%) had their medications changed due to other reasons.

In order to further assess the effectiveness of telemedicine visits, we determined how often patients were referred to the EMU, had laboratory or diagnostic tests ordered, and referred to another specialist during the virtual encounters. Of 223 patients assessed via telemedicine, 18 (8.1%) were referred to the EMU (Table 2); while for the remaining patients, inpatient evaluation with continuous EEG was either deemed to be unnecessary (56.9%), or it had previously been completed (35.0%). Laboratory tests and referrals to another medical subspecialty were requested in 18.8% and 11.2% of patients, respectively (Table 2).

### 3.3. Assessment of patient satisfaction and future telemedicine preference

The responses to the survey questions were available in 160 patients (71.7%). Five patients (2.2%) declined an invitation to participate, and 58 patients (26%) were not reachable after three attempts to contact them. There were no significant differences

Table 2

Diagnostic and therapeutic interventions provided during telemedicine visits. AED, antiepileptic drug; EMU, epilepsy monitoring unit.

Intervention	Number of orders (%)
<i>AED regimen adjustment</i>	
Changed	86 (38.6)
Unchanged	137 (61.4)
<i>Referral to EMU</i>	
Provided	18 (8.1)
Deferred	127 (56.9)
Previously completed	78 (35)
<i>Diagnostic/laboratory tests</i>	
Ordered	42 (18.8)
Deferred	181 (81.2)
<i>Referral to other specialists</i>	
Provided	25 (11.2)
Deferred	198 (88.8)

in the distributions of age, sex, telemedicine visit type, epilepsy diagnosis, and usage of AEDs between the groups of patients who have participated in the survey and those who could not be reached (Supplementary Table 2).

The majority of patients who participated in the survey (76.9%) reported very high satisfaction from receiving care via telemedicine services and chose the maximal rating of 5/5 (Fig. 2). The high and intermediate degree of satisfaction with the corresponding ratings of 4/5 and 3/5 were reported by 33 (20.6%) and four (2.5%) patients, respectively (Fig. 2). None of the responders selected a grade lower than 3/5. The degree of satisfaction tended to correlate with the distance from the epilepsy clinic to their residence ( $p = 0.05$ , Spearman rho = 0.15, Fig. 3). Specifically, patients who lived further from the epilepsy clinic tended to give a higher positive rating to their experience with their telehealth visit compared to those who resided closer to the clinic. There was no association between the patients' satisfaction scores and whether the patients completed visits via a video or telephone format ( $p = 0.47$ , Wilcoxon test). Furthermore, there was no difference in the satisfaction scores between the new and return patient groups ( $p = 0.94$ , Wilcoxon test, Supplemental Table 1).

When asked about their familiarity with the technology, the majority of patients (78.8%) reported having previous experience with video calls. Patients who indicated that they have used video platforms in the past were more than 10 years younger than those who did not have experience with video calls prior to their clinic encounters (median age 32.5 (IQR: 25–49) and 43 (IQR: 31–61) years, respectively;  $p = 0.02$ ). There was no association between the age of the patients and other survey parameters (Supplemental Table 1). The convenience of using the secure video platform integrated into the electronic medical record system was regarded as being “very easy” by sixty-three patients (39.6%). However, eighteen (11.3%) and twenty-nine patients (18.2%) reported that the ease of using the embedded platform was intermediate and difficult or very difficult, respectively (Fig. 2).

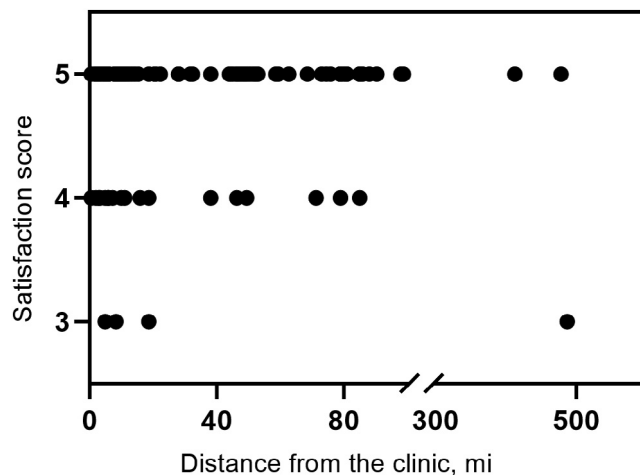


Fig. 3. Scatter plot showing correlation between distance from clinic (geodetic distance between patients' residence and epilepsy clinic) and satisfaction scores.

To determine the potential longevity of telemedicine services for epilepsy, we asked the patients about the likelihood to continue care via the telemedicine format after the pandemic is no longer a concern. More than two-thirds of the patients (68.2%) responded that they would definitely (43.8%) or probably (24.4%) use telemedicine services in the future, provided that their symptoms remained stable. On the other hand, 11.3% of patients with stable symptoms stated that they would probably or definitely not use this format for their care in the future (Fig. 2). Of the 160 patients who responded to the telephone survey, the majority (55%) responded that they would prefer a face-to-face assessment if their symptoms worsened. Among the factors that favorably influenced patients' decision to choose telehealth for epilepsy instead of

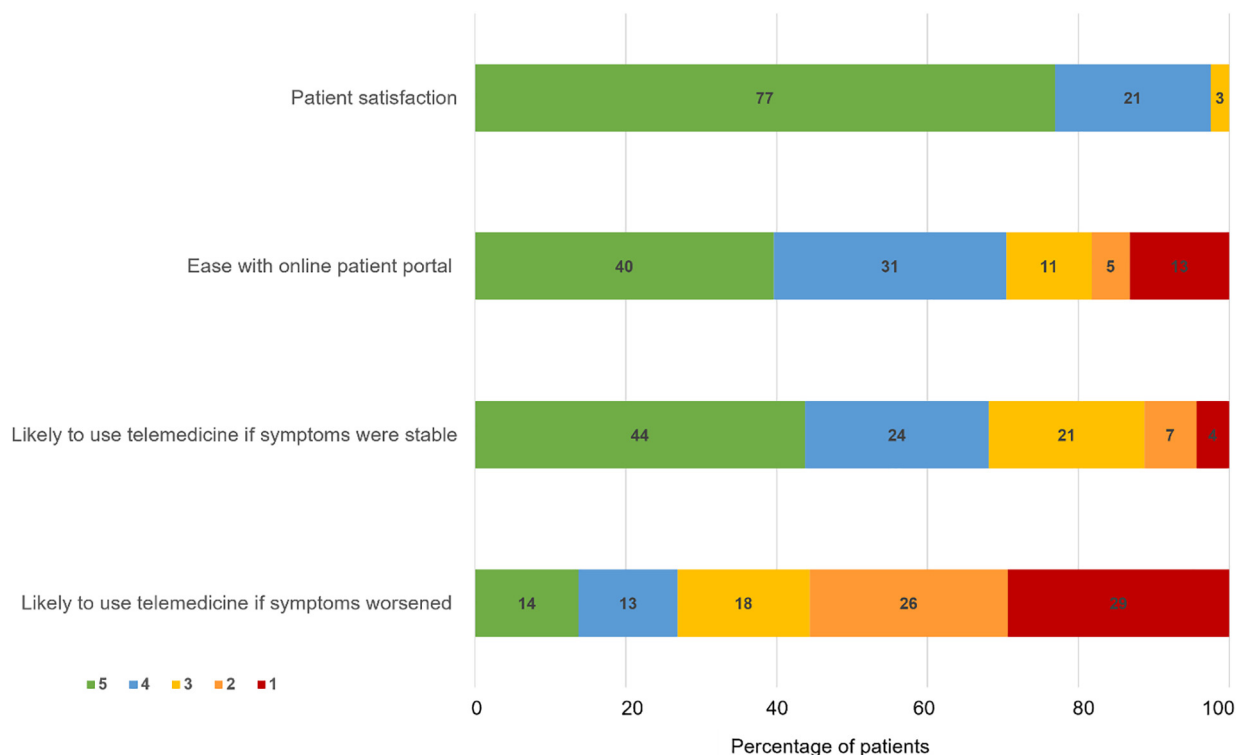


Fig. 2. Responses to the survey questions on satisfaction with telehealth visits and future telemedicine preference. Responses were graded on a Likert scale with 5 and 1 being the most and the least favorable, respectively.

face-to-face visits, inclement weather and lack of transportation were reported most frequently (68.8% and 58.8%, respectively).

### 3.4. Assessment of cost savings attributable to use of telemedicine services

Patients seen via telemedicine resided on average  $47.7 \pm 6.0$  mi (mean  $\pm$  SEM) away from the epilepsy center where they previously received face-to-face care. Notably, 58 patients (26%) lived more than 60 miles away from the clinic (Fig. 4). Assuming that they would have used a car as the main mode of transportation to their clinic appointments, a conservative estimate of savings in gas cost and time cost in the patients seen via telemedicine was  $\$30.20 \pm 3.8$  per visit.

## 4. Discussion

In the present study, we demonstrated that ambulatory care for epilepsy delivered in a telehealth format can be arranged with high effectiveness to address clinical needs of patients with seizures. Despite technical limitations, telehealth services were regarded as satisfactory by the majority of patients, and care delivered in this format provided an economic benefit due to the reduced need for transportation. Importantly, given that our assessment was conducted during the peak of the COVID-19 pandemic, our data suggest that continuity of care and assessment of new patients with seizures is feasible even at times of unprecedented strain on hospital resources.

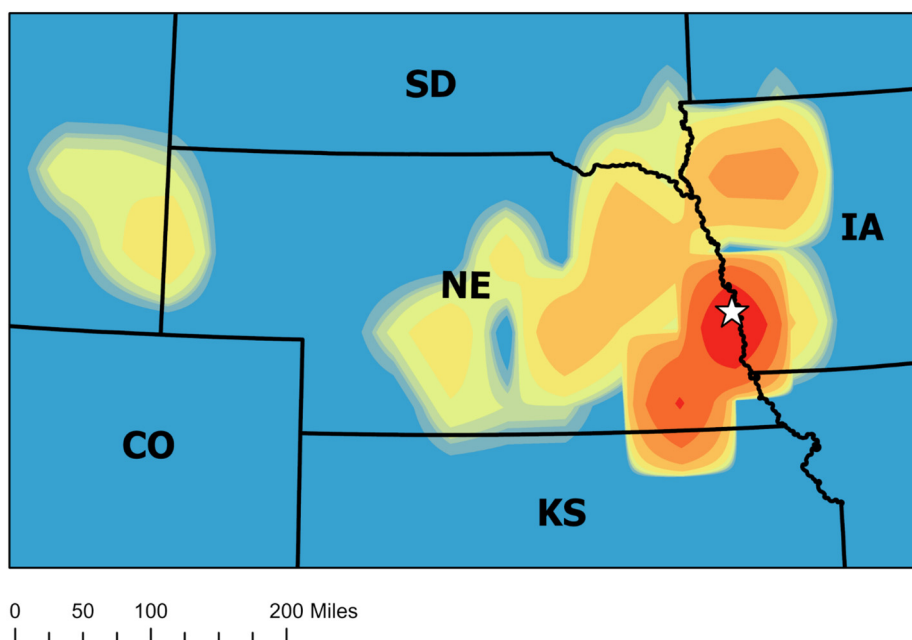
The basic demographic characteristics of patients with epilepsy in our study was similar to that previously reported in traditional ambulatory care clinic settings, including our epilepsy clinic [20,31]. Consistent with previous studies, the majority (53.8%) of patients seen via telemedicine in our clinic had focal epilepsy [32,33]. Furthermore, the proportion of patients with medically refractory epilepsy in our cohort was similar to that previously reported in the epidemiological studies [34]. We noted that over 8% of new and returning patients seen via telemedicine during the pandemic were referred to the EMU. This proportion is compa-

rable to the average monthly rates of EMU referrals from our ambulatory clinics in 2019 (unpublished data). Since the majority of long-term EEGs in the EMU is obtained for diagnostic purposes, these findings confirm that telemedicine visits could be as effective as traditional face-to-face clinic visits in providing referrals to diagnostic EEGs.

We determined that with coordinated help from the clinic staff, the majority of patients with epilepsy in our clinic (85.7%) were able to successfully complete a telemedicine visit with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) compliant audio-video technology. However, 18.2% of patients regarded their experience with the on-line portal as difficult or very difficult. Anecdotal experience during interactions with patients during the pandemic revealed barriers including inability of some patients to understand the steps necessary for a successful encounter as well as the lack of familiarity with the device settings or capabilities of synchronous audio-visual platforms. Similar technological difficulties that resulted in poor patient satisfaction have been reported in other studies on telemedicine [17,35–38].

Consistent with previous studies on the traditional telehealth services in epilepsy and our own experience with telehealth outside of the pandemic era (unpublished data), greater than two-thirds of the patients were highly satisfied with their care in a telehealth format [27,38,19]. The overwhelming majority of patients (89%) stated that they would prefer to continue the visits via telehealth if their symptoms remained stable. The interest in continued care via telemedicine was reported in a recent study assessing pediatric neurology care during the COVID-19 pandemic [39]. On the other hand, only 44.4% of patients in our study indicated that they would continue telemedicine if their seizure control deteriorated. This is consistent with the premise that higher seizure frequency results in higher usage of healthcare services [40]. Overall, our data suggest that seizure control can be used as one of the factors to determine if patients can be satisfactorily assessed via telehealth in future epidemiological and environmental disasters when the opportunities for face-to-face interactions are limited.

Our patient population (Fig. 4) was derived from three contiguous states in the Midwest with a total area of 210,877 square miles



**Fig. 4.** Geographic distribution of patients assessed in the tele epilepsy clinic during the COVID-19 pandemic. Red indicates areas with the highest number of patients who accessed telemedicine, while the blue represents areas with the fewest number of patients who accessed telemedicine. The star marks the location of the UNMC epilepsy clinic.

and a population of 5.96 million. These regions have limited availability of subspecialty neurologic care; thus, patients often spend 4–6 h to travel to their clinic appointments. As expected, patients residing further from the clinic tended to give a higher satisfaction score for their tele-epilepsy visit compared to those who lived closer to the clinic. Many people with epilepsy are unable to drive; therefore, the inconvenience of finding the means of transportation is alleviated for those with available telehealth services. Patients may be aware that seeing a physician from home is financially beneficial because of the reduced travel expense. Thus, a conservative estimated cost saving of over \$30 per visit for the patients in our study is considerable and cannot be understated [41,42]. The costs of additional transport and other travel-related expenses (e.g. taking time off work) were not factored into our calculations; therefore, the true magnitude of savings may be even higher. Among five factors listed in the survey as determinants of the future use of telehealth, inclement weather and lack of transportation were chosen by the majority of patients to be determinants of their choice of telehealth over conventional face-to-face care. We expect telemedicine to be an effective tool to improve clinic “no shows rates” [41,42] which often spike in the winter months.

The limitation of this study includes a possibility of the referral bias given that the study was conducted at a single level-4 epilepsy center that provides care to patients with intractable seizures and complex epilepsy syndromes. Therefore, generalization of our findings to other patient populations (e.g., those at community hospitals and in rural areas) may not be possible. The participation in the telephone survey on satisfaction was voluntary, which may introduce a selection bias; and responses from the patients who chose to participate in the study may not be representative of the entire clinic population. Furthermore, we did not study the contributions of racial disparities and disabilities on our patient cohort that have been previously reported to limit access to telemedicine [17,43–46]. A geodetic distance rather than driving distance was used in calculation of cost savings that can lead to underestimation of the actual magnitude of savings.

In summary, we showed that rapid implementation of telemedicine service allowed for continued access to specialty epilepsy care during the pandemic. This approach was associated with high patient satisfaction, cost savings, and was preferred over the traditional care format by the majority of patients with stable symptoms. We provide evidence for the effectiveness of in-home telemedicine in epilepsy care during the pandemic and the prospect of its success beyond the present epidemiological emergency.

Our study makes the following four key observations:

1. Patients with epilepsy can be evaluated effectively via telemedicine during an epidemiological crisis.
2. Patients expressed high satisfaction with telemedicine services.
3. Patients reported a preference for telemedicine services when their epilepsy symptoms were stable, but preferred a face-to-face evaluation if their symptoms worsened.
4. Telemedicine provides cost savings when compared to the traditional face-to-face care.

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## Declaration of interest

O. Taraschenko receives research funding from the American Epilepsy Society and reports no conflict of interest related to this manuscript. The remaining authors have no conflicts of interest.

## Author contributions

P.D and O.T. contributed to the study concept and design. P.D., W.B., M.B., T.J., L.A.J., A.M., C.P., A.S., A.V., and O.T., contributed to acquisition of data. P.D., K.K.S., H.W., O.T., contributed to analysis and interpretation of the data. P.D., L.A.J., A.S., A.V., K.K.S. and O.T contributed to drafting the manuscript.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.yebeh.2020.107740>.

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