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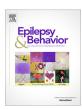
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Demographic and technological factors influencing virtual seizure clinic visit satisfaction before and during the Covid-19 pandemic in rural Hawaii



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ABSTRACT

Background: Telemedicine clinic visits traditionally originated from spoke clinic sites, but recent trends have favored home-based telemedicine, particularly in the time of Covid-19. Our study focused on identification of barriers and factors influencing perceptions of care with use of home-based telemedicine in patients with seizures living in rural Hawaii. We additionally compared characteristics of patients using telemedicine versus in-person clinic visits prior to the Covid-19 pandemic.

Methods: For the retrospective portion of our study, we queried charts of adult outpatients treated by the two full-time epileptologists at a Level 4 epilepsy center accredited by the National Association of Epilepsy Centers between November 2018 and December 2019. We included patients who live on the neighbor islands of Hawaii but not on Oahu, i.e., patients who would require air travel to see an epileptologist. There had been no set protocol at the epilepsy center for telemedicine referral; our practice had been to offer telemedicine visits to all neighbor island patients when felt to be appropriate. We collected demographic and clinic visit data.

For the prospective portion we surveyed neighbor island patients or their caregivers, seen via homebased telemedicine between March 2020 and December 2020. We obtained verbal consent for study participation. Survey questions addressed satisfaction with clinical care, visit preferences, and potential barriers to care.

Results: In a 14-month period prior to the Covid-19 pandemic, 75 (61%) neighbor island patients were seen exclusively in-person in seizure clinic while 47 (39%) had at least one telemedicine visit, 39% of patients seen only in-person were female whereas 38% of patients seen by telemedicine were female. Patients seen in-person had an older median age (47.2 years) compared to those seen at least once by telemedicine (42.4 years). The no-show rate was 13% for in-person visits versus 4% for telemedicine vis-

Among patients seen in person, 17% were Asian, 32% Native Hawaiian, and 47% White, whereas patients seen by telemedicine were 15% Asian, 23% Native Hawaiian, and 57% White. Patients who were seen in person lived in zip codes with median household income of \$68.516 and patients who were seen by telemedicine lived in zip codes with median household income of \$67,089. Patients who were seen in person lived in zip codes in which 78% of the population had access to broadband internet, whereas patients who were seen by telemedicine lived in zip codes in which 79% of the population had access to broadband internet.

During the Covid-19 pandemic, we surveyed 47 consecutive patients seen by telemedicine, 45% female with median age of 33 years. Telemedicine connection was set up by the patient in 74% of cases, or by the patient's mother (15%), other family member (9%), or other caregiver (2 %). Median patient satisfaction score was 5 ("highly satisfied") on a 5-point Likert scale with mean score of 4.6. Telemedicine visit was done using a smartphone by 62% of patients, a computer by 36% of patients, and a tablet by 2% of patients. A home WiFi connection was used in 83% of patients.

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Conclusions: Home-based telemedicine visits provide a high-satisfaction method for seizure care delivery despite some obstacles. Demographic disparities may be an obstacle to telemedicine care and seem to relate to race and possibly age, rather than to sex/gender, household income, or access to broadband internet. Additionally, despite high satisfaction overall, more patients felt the physical exam was superior at in-person clinic visits and more patients expressed a preference for in-person visits. During the Covid-19 pandemic when there may be barriers to in-person clinic visits, home-based telemedicine is a feasible alternative.

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1. Introduction

Telemedicine clinic visits have traditionally originated from spoke clinic sites but recent trends have favored home-based telemedicine, particularly in the time of Covid-19. Even prior to the pandemic, there had been a trend toward telemedicine visits to the home and to the smartphone rather than in hospitals and clinics [1] with research suggesting equivalent efficacy. Patients with seizures and epilepsy in particular benefit from home-based telemedicine since driving restrictions are common within this population. Additionally, in the state of Hawaii, patients living on the "neighbor islands" (i.e., Hawaiian Islands that are not Oahu) often have to fly to Oahu for specialty care; this can be avoided with home-based telemedicine.

In comparing patients with epilepsy seen in-person in the clinic and those seen at a telemedicine clinic, one prior study found no difference in demographics, number of seizures, hospitalizations, and emergency room visits between the two groups [2]. Patients with epilepsy had improved seizure control with a successful pilot of telemedicine clinic visits [3]. Visits at a telemedicine clinic helped reduce costs among patients with epilepsy [4]. All these studies, however, involved satellite telemedicine clinic sites rather than home telemedicine clinic visits.

More recently during the COVID-19 pandemic, telehealth has been ubiquitous with >90% of American Epilepsy Society survey responders using telehealth in some capacity [5]. Use of videoconferencing to patients' personal devices is now commonplace [6]. Recent research studies have confirmed that most patients with epilepsy are highly satisfied with care received during telemedicine appointments [6,7]. Benefits were noted to include "improved access, decreased no-show rates, observations of the home environment, participation of families/caregivers, general efficiency of the visits, flexibility for patients and providers, enhanced integration with multidisciplinary teams, and increased access to psychosocial care providers [5]." Patients reported a preference for continuing telemedicine use and there was an estimated cost saving to patients attributable to telemedicine [8].

Although the benefits of clinic visits by telemedicine are clear, the barriers and pitfalls are not well characterized. The loss of an in-person interaction between patient and physician may affect the traditional doctor-patient relationship and, in the case of teleneurology, the ability to perform a detailed neurologic exam is limited [9]. Additionally, potential unconscious provider biases (e.g., discrimination based on age or gender), the challenges of technology, and perception of visit quality may be obstacles for patients considering the option of telemedicine clinic visits.

Our present study focused on the clinical and technical experience of patients living on the neighbor islands of Hawaii seen in seizure clinic via home-based telemedicine. At our tertiary care center in Honolulu, Hawaii on the island of Oahu, the epileptologists offer telemedicine clinic visits to patients with seizures, particularly to those on the neighbor islands who would otherwise require plane travel to see an epilepsy specialist. Outcome measures included the uptake and usage of telemedicine, demograph-

ics of patients using telemedicine versus patients who are not using telemedicine, patient satisfaction with their clinical and technical experience, and clinic visit preferences. We additionally compared the characteristics of patients using telemedicine versus in-person clinic visits prior to the Covid-19 pandemic. Evaluation of these outcome measures allowed for identification of potential barriers to telemedicine uptake or factors that negatively influence perceptions of care.

2. Materials and methods

This study was conducted in compliance with the protocol approved by the Research and Institutional Review Committee, and according to Good Clinical Practice standards, applicable federal regulations, and Queen's Medical Center research institutional policies and procedures.

2.1. Retrospective component

We queried the charts of all adult outpatients treated by the two full-time epileptologists at a Level 4 epilepsy center accredited by the National Association of Epilepsy Centers (NAEC) between November 1, 2018 and December 31, 2019. We chose a 14month period because it is required that patients seen for ongoing care are seen at least annually in our clinic so this would ensure that most eligible patients are captured in the study. All patients receiving ongoing care in this clinic would have a diagnosis of epilepsy or seizures (including psychogenic nonepileptic seizures). We included only patients with primary addresses in the state of Hawaii but not on Oahu where the epilepsy center is located, i.e., patients who would require air travel to see an epileptologist; this was approximately 20% of our patients. There had been no set protocol at the epilepsy center for telemedicine referral; our practice had been to offer telemedicine visits to all neighbor island patients where appropriate by their epileptologist.

From this cohort, we collected basic demographic information from their medical chart including age, date of birth, sex, preferred language, race, ethnic background, and zip code. We also collected information about each patient's clinic visits including the total number of in-person and telemedicine clinic visits, and number of no-shows by appointment type during the 14-month period.

We additionally used zip code and American Community Survey 2014–2018 averaged data to identify median household income and percentage of households with a broadband internet subscription during that 5-year period [10].

2.2. Prospective component

Between March 2020 and December 2020, we collected questionnaire responses from adult patients via telemedicine after their seizure clinic appointments. Medical students first obtained verbal consent for study participation then used the scripted questionnaire to ask patients basic questions about their satisfaction with the level of their clinical care, visit preferences, and barriers to tel-

emedicine. They were additionally asked questions about how they access telemedicine (connection method, device make and model) and barriers to accessing telemedicine. For patients unable to participate due to decisional impairment, the caregiver present at the patient visit was asked to participate in the study and complete the questionnaire.

We enrolled 47 consecutive (based on research staff availability) patients or caregivers who met inclusion criteria and consented to study participation. Baseline characteristics of study subjects were summarized using frequencies, percentages, and descriptive statistics.

3. Results

In a 14-month period prior to the Covid-19 pandemic, 75 (61%) neighbor island patients were seen exclusively in-person in seizure clinic ("patients seen in person") while 47 (39%) had at least one telemedicine visit ("patients seen by telemedicine"). The noshow rate was 13% for in-person visits versus 4% for telemedicine visits. Table 1 displays characteristics of patients seen in person versus patients seen by telemedicine.

Race data were collected from the electronic medical record and analyzed. Fig. 1 displays the race of patients seen in person versus patients seen by telemedicine. These data can be compared to 2019 United States Census Bureau data which describe the racial demographics of the population of Hawaii: American Indian and Alaska Native 0.4%, Asian 37.6%, Black 2.2%, Native Hawaiian and other Pacific Islander 10.1%, White 25.5%, two or more races 24.2% [11].

We additionally used zip code and American Community Survey 2014–2018 averaged data to identify median household income and percentage of households with a broadband internet subscription during that 5-year period [10]. Patients who were

 Table 1

 Characteristics of patients seen in person versus by telemedicine.

	In-Person (n = 75)	Any Telemedicine (n = 47)
Mean number of visits (SD)	1.5 (0.8)	2.6 (1.8)
Percent female (unique patients)	39%	38%
Median age (years)	47.2	42.4

SD = standard deviation.

seen in person lived in zip codes with median household income of \$68,516 whereas patients who were seen by telemedicine lived in zip codes with median household income of \$67,089. Patients who were seen in person lived in zip codes in which 78% of the population had access to broadband internet whereas patients who were seen by telemedicine lived in zip codes in which 79% of the population had access to broadband internet.

We surveyed 47 consecutive (based on research staff availability) patients or their caregivers seen by telemedicine who met inclusion criteria and consented to study participation. There were 113 patients who met inclusion criteria and were seen at a telemedicine visit during the survey window so we surveyed 42% of eligible patients. Surveyed patients were 45% female with median age of 33 years. Telemedicine connection was set up by the patient themselves in 74% of cases, or by the patient's mother (15%) or other family member (9%) or other caregiver (2 %).

Median patient satisfaction score was 5 ("highly satisfied") on a 5-point Likert scale with mean of 4.6. 83% of patients used a home WiFi connection, 13% used their cellular data plan for access, and the others accessed the internet by alternate means (e.g., using WiFi at a friend/family/neighbor's house or other method). 62% used a smartphone while 36% used a computer and 2% used a tablet. See Table 2 for responses to additional questions.

In evaluation of the survey data, there was a significant interaction between age and "tech-savviness," i.e., whether the patient felt it was challenging to connect to a telemedicine visit because they did not know enough about technology (p < 0.01). Younger patients who reported lower technical knowledge were less satisfied with their care whereas level of technical knowledge had less of an impact on visit satisfaction in older patients (Fig. 2).

4. Discussion

Home-based telemedicine visits have become ubiquitous during the COVID-19 pandemic and have been shown to be a high-satisfaction method for seizure care delivery. This study highlights that some demographic and technological factors may be obstacles to telemedicine care or may influence patients' perceptions of care.

In our sample, racial disparities in accessing telemedicine appeared to play a larger role than sex/gender, household income, or access to broadband internet. White patients made up a higher proportion of those being seen by telemedicine whereas Native

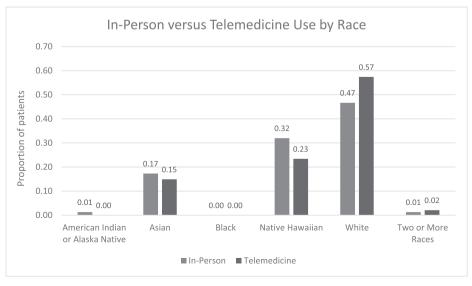


Fig. 1. Race of patients seen in person versus by telemedicine.

Table 2Preferences of patients seen by telemedicine during Covid-19 pandemic.

	True (%)	False (%)
I would rather see my doctor in person than on a screen.	30 (64)	17 (36)
I feel like the physical exam might be less detailed during a telemedicine visit.	36 (77)	11 (23)
I find it challenging to connect to a telemedicine visit because I do not know enough about technology.	7 (15)	40 (85)
I find it challenging to connect to a telemedicine clinic because my internet connection is not very good.	8 (17)	39 (83)
I feel like the visit quality is better with in-person clinic visits.	24 (51)	23 (49)
I enjoy visiting Oahu when I have doctor's appointments there.	30 (64)	17 (36)
I have had experience with telemedicine appointments in other clinics before, outside of seizure clinic.	20 (43)	27 (57)

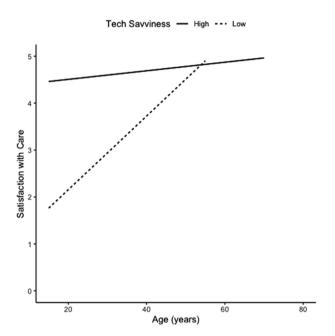


Fig. 2. Relationship between patient satisfaction and "tech savviness".

Hawaiian patients tended to be seen in person. The finding of racial disparity in telemedicine access is aligned with that seen in other areas of medicine such as hypertension and diabetes care [12], geriatrics care [13], and care of patients with liver disease [14]. To our knowledge, this is the first study to examine telemedicine use in Native Hawaiians with seizures and epilepsy. There is a paucity of literature on Native Hawaiians with seizures and epilepsy, so we hope to expand upon this in future studies.

While an exploratory finding, it is notable that older patients may be more satisfied with telemedicine care even if not "techsavvy." Younger patients with lower self-reported technology skills have a lower satisfaction of care whereas older patients appear to have high satisfaction of care even if they report lower technology skills. One possible explanation is that younger patients have higher expectations about the ease of use of the technology involved in telemedicine visits. The fact that older patients have high satisfaction with telemedicine care suggests that telemedicine services should be offered across the age spectrum.

Patients felt that their physical exam was superior at in-person clinic visits and they expressed a preference for in-person visits. That said, they still reported high levels of satisfaction with their telemedicine care. One contributing factor may be the higher frequency of telemedicine clinic visits. In the retrospective portion of the study, patients seen by telemedicine had a higher mean number of visits during the study period compared to patients seen exclusively in person. Although the higher visit frequency may be confounded by differing demographic or medical factors between

the two groups, it is apparent that telemedicine visits allow for easier clinic access. During the Covid-19 pandemic when there may be increased barriers to in-person clinic visits, home-based telemedicine is a feasible alternative.

One study weakness was the low number of patients surveyed. We were able to survey only 42% of eligible patients based on research staff availability though anecdotally, no patients declined to be surveyed. Additionally, our study design did not allow for survey data to be linked back to protected health information to minimize patient risk and to avoid the challenges of obtaining written consent over telemedicine.

Our study is consistent with many others showing high patient satisfaction with telemedicine seizure care. We have expanded this literature by identifying that specific demographic and technological factors may be obstacles to telemedicine care or may influence patients' perceptions of care. These factors may be verified by future study of which patients were lost to follow-up during the COVID-19 pandemic. Identification of such factors will allow for disparities to be addressed at a systemic level. Patients expressed a preference for in-person visits and tend to enjoy visitation of Oahu, but it still appears that telemedicine is here to stay.

Conflicts of interest

VSSW, MKW, CKA, LNA, EJT, AGS, SMA, MAK, and MAR report no conflicts of interest or financial disclosures.

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