

Early Impact of the COVID-19 Pandemic on Outpatient Neurologic Care in Hawai'i

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Abstract

In March 2020, Hawai'i instituted public health measures to prevent the spread of Coronavirus disease 2019 (COVID-19), including stay-at-home orders, closure of non-essential businesses and parks, use of facial coverings, social distancing, and a mandatory 14-day quarantine for travelers. In response to these measures, Hawai'i Pacific Neuroscience (HPN) modified practice processes to ensure continuity of neurological treatment. A survey of patients was performed to assess the impact of the COVID-19 pandemic and pandemic-related practice processes for quality improvement. Overall, 367 patients seen at HPN between April 22, 2020, and May 18, 2020, were surveyed via telephone. Almost half (49.6%) participated in a telemedicine appointment, with the majority finding it easy to use (87.4%) and as valuable as face-to-face appointments (68.7%). Many (44.5%) patients said they would have missed a health care appointment without the availability of telemedicine, and 47.3% indicated they might prefer to use telemedicine over in-person appointments in the future. Many reported new or worsening mental health problems, including depression (27.6%), anxiety (38.3%), or sleep disturbances (37.4%). A significant number reported worsening of their condition, with 33.1% of patients who experience migraines reporting increased symptom severity or frequency, 45.8% patients with Alzheimer's disease reporting worsened symptoms, 38.5% of patients with Parkinson's disease who had a recent fall, and 50.0% of patients with multiple sclerosis experiencing new or worsened symptoms. Insights from this survey applied to the practice's pandemic-related processes include emphasizing lifestyle modification, screening for changes in mental health, optimizing treatment plans, and continuing the option of telemedicine.

Keywords

COVID-19, pandemic, outpatient care, telemedicine, survey

Acronyms and Abbreviations

COVID-19 = Coronavirus disease 2019
ER = emergency room
HPN = Hawai'i Pacific Neuroscience
NHOPI = Native Hawaiian and Other Pacific Islander
QI = quality improvement
TIA = transient ischemic attack
US = United States

Introduction

While the United States (US) is experiencing difficult times due to the Coronavirus disease 2019 (COVID-19) pandemic, the disease burden has been unequally shared among each state.

In April 2020, Hawai'i's COVID-19 infection rate per capita was the third-lowest in the United States with 36 cases per 100 000 population, far below the national rate of 177 cases per 100 000.¹ Nevertheless, the highly contagious nature of the virus, the high proportion of asymptomatic carriers, relatively high mortality in the subset of patients afflicted with severe acute respiratory syndrome, along with constant media coverage and financial burden caused by quarantine, have contributed to heightened levels of anxiety among the public.²⁻⁴ Early government action in Hawai'i has been credited with "flattening the curve." These measures, beginning in March 2020, included stay-at-home orders, closure of non-essential businesses and parks, use of facial coverings, social distancing, and a mandatory 14-day quarantine for travelers.⁵ Though these measures promote public health and safety, it's important to identify unforeseen consequences on people and implement ways to mitigate these impacts.

Patients with neurological disease are vulnerable to mental and physical deterioration with limited access to health care or healthy lifestyle options. The prevalence of depression, one of the most common comorbid psychiatric disorders in patients with epilepsy, multiple sclerosis, and Parkinson's disease, is between 20% and 50%.^{6,7} An increase in depression incidence is clinically significant, as numerous studies have linked depression to increased all-cause mortality.⁸ Exercise is also important for neurological patients. Many patients have symptoms of neuromuscular weakness, leading to an inability to perform activities of daily living and a decline in quality of life.⁹ For patients with Parkinson's disease, studies have shown that those who regularly exercise had slower declines in mobility and health-related quality of life than non-exercisers.¹⁰ Additionally, exercise has been shown to improve depressive symptoms in patients with neurological disorders, such as multiple sclerosis, Parkinson's disease, and epilepsy.¹¹⁻¹³ Ultimately, ensuring patients at increased risk of decompensation are connected to health care services that protect their well-being is imperative.

With the advent of stay-at-home orders and new protective measures, health care facilities across the state hastened to adjust their previously routine procedures and protocols. The authors are associated with Hawai'i Pacific Neuroscience (HPN), a large neuroscience care and clinical research center that provides care

to over 20 000 patients annually with a multidisciplinary team of neurology, neurosurgery, physical medicine, rehabilitation, geriatrics, and sleep medicine health care professionals. Practice procedures were modified to follow recommendations from the Centers for Disease Control and Prevention and the American Academy of Neurology. In addition, HPN greatly expanded its telemedicine capacity to allow continuity of care for patients while minimizing coronavirus spread.

Due to these practice changes and concern for potential patient deterioration, a survey of patients was performed during the early stages of the COVID-19 pandemic. The purpose of this survey was to assess patients' needs and changes to accessing health care, general and mental well-being, and neurologic conditions to implement practice processes for quality improvement (QI). At the time of this study, no prior report investigated the observed health impact on patients with neurological conditions during the COVID-19 pandemic in a low disease prevalence area, such as Hawai'i.

Methods

A voluntary telephone survey was conducted on new and follow-up patients seen at HPN between April 22, 2020, and May 18, 2020, to investigate their health and well-being during the COVID-19 pandemic. Patients were seen in HPN locations across the state of Hawai'i: Honolulu, Kailua, and Waikēle on O'ahu island and Kona on Hawai'i island. Interviewers were trained in survey administration to ensure consistency of data collection. Surveys lasted about 15 minutes, and the surveyor documented patient responses to the survey in a de-identified online form in Google Docs (Google, Mountain View, CA). All patients gave verbal consent and acknowledged the right to decline the survey at any point. Patients were not offered incentives for survey completion. The study was conducted as a clinic-oriented, QI survey and was therefore deemed exempt from the Institutional Review Board. The inclusion criteria were the patients seen at HPN either in-person or via video teleconferencing during the above time frame. Patients who declined or failed to complete the survey were excluded from the study. When appropriate, the principal caregiver for the patient was interviewed.

HPN utilized the eClinicalWorks Electronic Health Record service (healow, Westborough, MA) for video teleconferencing appointments; this platform is compliant with all federal Health Insurance Portability and Accountability Act regulations. Patients were contacted by a designated telehealth team before their appointments to ensure connectivity and troubleshoot technological issues. Zoom (Zoom Video Communications, San Jose, CA) was available as a backup option if there were connectivity issues.

The survey questions addressed 4 areas related to the patients' outpatient experience: general issues regarding their care,

experience with telemedicine, general health and well-being, and disease-specific questions, and demographics. Patients with self-reported diagnoses of migraine, epilepsy, multiple sclerosis, Alzheimer's disease, Parkinson's disease, and cerebrovascular disease were asked tailored questions. Questions were easy to understand, requiring simple answers, such as affirmation ("yes" vs "no") or a change in condition ("increased," "decreased," "no change").

Descriptive statistics were conducted. Chi-square tests were run in IBM Statistical Product and Service Solutions (Version 23, IBM Corporation, Armonk, NY) to determine the relationship between participants' demographic characteristics and responses to survey questions regarding their perception of telemedicine and their general health and well-being.

Results

Out of the 928 patients seen across the HPN outpatient facilities from April 22, 2020, to May 18, 2020, telephone contact was established with 429 (46.2%) patients. Of those, 367 (85.5%) agreed to participate. Participant demographics are presented in Table 1. Participants had a median age of 56 years and a mean age of 54.1 years. Women accounted for 212 (57.8%) of the respondents. The most common racial and ethnic groups represented were White (n = 115, 39.7%), Native Hawaiian and Other Pacific Islander (NHOPI; n = 89, 30.7%), and Asian (n = 58, 20.0%). Patients were asked if they had been diagnosed with conditions of special interest to the researchers, including 118 (32.2%) with migraine, 24 (6.5%) with Alzheimer's disease, 48 (13.1%) with epilepsy or other seizure disorder, 35 (9.5%) with a history of stroke or transient ischemic attack (TIA), 13 (3.5%) with Parkinson's disease, and 4 (1.1%) with multiple sclerosis.

Access to health care appears generally unaffected, as most patients denied difficulty obtaining medications (91.0%) or difficulty attending scheduled doctor visits (75.5%) (Table 2). However, 16.4% of patients reported they avoided accessing health care for new health problems from March to May 2020.

Between March and May 2020, HPN encouraged patients to utilize telemedicine but offered in-person appointments if preferred. Half (49.6%) of respondents reported participating in a telemedicine appointment during this period (Table 2). Most patients who used telemedicine found that it was easy to use (87.4%) and was as valuable as a face-to-face appointment (68.7%). A little less than half of patients (44.5%) said they would have missed a health care appointment without the availability of telemedicine. Patients were asked if they would prefer to use telemedicine over in-person appointments in the future once the COVID-19 pandemic resolved. Close to half (47.3%) of respondents reported they would prefer telemedicine in the future, and an additional 20.3% said they might prefer telemedicine for some appointments.

Patients were also surveyed on how their mental health changed after March 2020. More than a quarter of surveyed patients reported new or worsening mental health problems, including depression (27.6%), anxiety (38.3%), or sleep disturbances (37.4%) (Table 2). Patients younger than 65 years were more likely to experience new or worsening sleep disturbances (44.1% vs 20.8%, $P < .001$) than their older peers (Table 3). Differences in depression (30.3% vs 20.8%, $P = .064$) and anxiety (40.2% vs 33.0%, $P = .197$) were also seen between the age groups but were not statistically significant.

Participants with 1 or more diagnoses of interest (ie, migraine, epilepsy, Alzheimer’s disease, Parkinson’s disease, multiple sclerosis, and cerebrovascular disease) accounted for 66.0% ($n = 242$) of the pool of participants (Table 4). Overall, 33.1% of patients who experience migraines reported increased symptom severity or frequency, 45.8% of patients with Alzheimer’s disease reported worsened symptoms, 38.5% of patients with Parkinson’s disease reported an increase in recent falls, and 50.0% of patients with multiple sclerosis reported new or worsened symptoms.

Discussion

Even though Hawai‘I, at the time of this writing, is one of the states with the least per capita COVID-19 infections, neurological patients and their health care have not been spared from the impact of the COVID-19 pandemic. The COVID-19 pandemic continues to shift the structure of health care rapidly. Amid this crisis, there is an opportunity to improve upon the approach to the care of neurological patients. In this spirit, health care providers have turned to each other to determine the best procedures to mitigate the effect of the pandemic on their practices.¹⁴⁻¹⁷

The strict measures imposed to safeguard public health in Hawai‘I have had significant economic repercussions, as the state is heavily dependent on tourism. Data from the Department of Labor and Industrial Relations shows that Hawai‘i’s unemployment rate in April 2020 jumped to 23.5%, in contrast to a pre-COVID-19 unemployment rate of 2.5%. Hawai‘i’s economic growth rate is expected to drop by 12.1% in 2020.¹⁸ Data from this survey reflects employment loss seen in the greater population, with 22.4% of those employed before the start of the pandemic reporting loss of employment.

With health insurance potentially tied to employment, there is a concern that patients would have difficulty accessing health care. Of those surveyed, most responses to questions regarding medical care access (eg, challenges obtaining medications, missing appointments, and lack of health insurance) did not suggest a negative impact. However, HPN noted a significant reduction of about 40% of the monthly outpatient caseload during the 4 weeks the survey was conducted, limiting the generalizability of these results. The mandatory stay-at-home orders, financial concerns, and pandemic-related fears could have contributed to decreased visits.

Age (years)	
<29 (%)	41 (11.2)
30-49 (%)	107 (29.2)
50-64 (%)	113 (30.8)
≥65 (%)	106 (28.9)
Median	56
Mean	54.1
Sex	
Men (%)	155 (42.2)
Women (%)	212 (57.8)
Race/ethnicity	
White (%)	115 (39.7)
NHOPI (%)	89 (30.7)
Asian (%)	58 (20.0)
Hispanic (%)	9 (3.1)
African American (%)	4 (1.4)
American Indian/Alaskan Native (%)	2 (0.7)
Other/Mixed (%)	13 (4.5)
Missing (%)	77 (21.0)
Selected Diagnoses	
Migraine	118 (32.2)
Alzheimer’s Disease	24 (6.5)
Epilepsy	48 (13.1)
Parkinson’s Disease	13 (3.5)
Multiple Sclerosis	4 (1.1)
Stroke/TIA history	35 (9.5)

Abbreviation: TIA, transient ischemic attack.

Telemedicine may assist in maintaining access to health care.¹⁹ A clinically relevant number of patients (16.4%) reported they avoided accessing health care for new health problems since the start of the pandemic. A national survey estimated that 40.9% of US adults avoided medical care during the pandemic because of concerns about COVID-19. Other than the fear of exposure to COVID-19, barriers to care include reduced availability of public transportation, increased financial burden, loss of health insurance, and adherence to public health recommendations.²⁰ Telemedicine has the opportunity to increase access to health care by reducing the risk of exposure, decreasing transportation needs, and limiting time taken off from work. Of patients who had a telemedicine appointment, 44.5% responded they would have missed that appointment without the availability of telemedicine. The ability to attend a medical appointment from one’s own home is even more vital in Hawai‘I, where patients from neighboring islands (Maui, Kaua‘I, Moloka‘I, and Hawai‘I islands) routinely fly into Honolulu (O‘ahu) for specialized medical care. The state-mandated 14-day quarantine for travelers, including inter-island travel, could make it

Table 2. Self-reported Changes in Access to Health Care, Telemedicine Usage, and Mental and General Well-Being During the COVID-19 Pandemic

Access to health care	N	Yes n (%)	No n (%)			
Difficulty obtaining medications	367	33 (9.0)	334 (91.0)			
Missed medical appointment	367	90 (24.5)	277 (75.5)			
Unable to obtain diagnostic testing	367	39 (10.6)	328 (89.4)			
Avoided medical care despite new health concern	367	60 (16.4)	307 (83.7)			
Difficulty with health insurance premiums or coverage	367	26 (7.1)	341 (92.9)			
Lost health insurance	367	4 (1.1)	363 (98.9)			
Telemedicine	N	Yes n (%)	No n (%)	Maybe n (%)		
Participated in a telemedicine visit	367	182 (49.6)	185 (50.4)	0 (0.0)		
Telemedicine was easy to use	182	159 (87.4)	23 (12.6)	0 (0.0)		
Telemedicine is as valuable as in-person appointments	182	125 (68.7)	57 (31.3)	0 (0.0)		
Would have missed an appointment without the option of telemedicine	182	81 (44.5)	101 (55.5)	0 (0.0)		
Would prefer telemedicine over in-person appointments in the future	182	86 (47.3)	59 (32.4)	37 (20.3)		
Mental and general well-being	N	Yes n (%)	No n (%)			No Response n (%)
New or worsening depression	367	101 (27.6)	265 (72.4)			1 (0.0)
New or worsening anxiety	367	140 (38.3)	226 (61.8)			1 (0.0)
New or worsening sleep problems	367	137 (37.4)	229 (62.6)			1 (0.0)
		Increased n (%)	Decreased n (%)	No change n (%)		
Frequency of exercise	367	29 (7.9)	132 (36.0)	132 (36.0)	74 (20.1)	
Weight change	367	89 (24.3)	45 (5.2)	232 (63.4)		
		Increased n (%)	Decreased n (%)	No change n (%)	None n (%)	
Alcohol consumption	367	22 (6.0)	19 (5.2)	171 (46.7)	154 (42.1)	
		Remained employed n (%)	Lost employment n (%)	Retired before March 2020 n (%)	Unemployed before March 2020 n (%)	
Employment	367	191 (52.0)	55 (15.0)	88 (24.0)	33 (9.0)	

prohibitively difficult for those patients to obtain the care they need in person.⁵ Some advantages of telemedicine over in-person visits may include reductions in travel (time and cost savings), care-partner burden, and indirect costs (time off work).²¹⁻²³

Telemedicine offers quality care to neurologic patients without a significant decrease in patient satisfaction. While telemedicine may have limitations for detailed neurological examinations, studies of its use in neurologic conditions demonstrated the ability to achieve appointment goals from both a patient and clinician perspective.^{24,25} Studies of telemedicine in neurology practices before the COVID-19 pandemic likewise showed high marks of patient satisfaction.^{22,23} In this study, most telemedi-

cine users responded positively in terms of their ease of use (87.4%) and value (68.7%). Almost half of the telemedicine users reported they would prefer telemedicine over in-person appointments in the future (47.3%), with an additional 20.3% stating that they would prefer telemedicine in some instances. The increased exposure of patients to telemedicine during the pandemic will likely have long-lasting changes to how health care is delivered.

The COVID-19 pandemic has had a serious impact on the mental health of the public. Pandemic-related anxiety includes fear of contagion through exposure to carriers and contaminated surfaces, fear of foreigners, fear of economic consequences,

Table 3. Relationship Between Participant Demographic Characteristics and Self-Reported Changes in Mental Health During the COVID-19 Pandemic

	N	New/Worsening Depression n (%)	New/Worsening Anxiety n (%)	New/Worsening Sleep Problems n (%)
Total	367	101 (27.6)	140 (38.2)	137 (37.4)
Age (years)				
Younger than 65	261	79 (30.3)	105 (40.2)	115 (44.1)
65 and older	106	22 (20.8)	35 (33.0)	22 (20.8)
		$\chi^2 = 3.420, P = .064$	$\chi^2 = 1.661, P = .197$	$\chi^2 = 17.503, P < .001$
Sex				
Men	155	39 (25.2)	55 (35.5)	51 (32.9)
Women	212	62 (29.2)	85 (40.1)	86 (40.6)
		$\chi^2 = .749, P = .387$	$\chi^2 = .807, P = .369$	$\chi^2 = 2.247, P = .134$
Race/ethnicity				
NHOPI	88	28 (31.8)	88 (34.1)	40 (45.5)
Non-NHOPI	202	56 (27.7)	80 (39.6)	71 (35.1)
		$\chi^2 = .500, P = .480$	$\chi^2 = .791, P = .374$	$\chi^2 = 2.756, P = .097$

Abbreviation: NHOPI, Native Hawaiian and Other Pacific Islander.

Table 4. Self-Reported Changes in Specific Neurologic Conditions During the COVID-19 Pandemic^a

Migraine	N	Increased n (%)	Decreased n (%)	No Change n (%)
Symptom severity or frequency	118	39 (33.1)	4 (3.4)	75 (63.6)
		Yes n (%)	No n (%)	
Used more abortive therapy	118	19 (16.1)	99 (83.9)	
Stroke or TIA history	N	Yes n (%)	No n (%)	
Change in diet	35	8 (22.9)	27 (77.1)	
Recent symptoms	35	12 (34.3)	23 (65.7)	
Received treatment for symptoms	12	9 (75.0)	3 (25.0)	
Alzheimer's disease	N	Yes n (%)	No n (%)	
Worsened symptoms	24	11 (45.8)	13 (54.2)	
Epilepsy or other seizure disorder	N	Yes n (%)	No n (%)	
Recent seizure	48	17 (35.4)	31 (64.6)	
Parkinson's disease	N	Yes n (%)	No n (%)	
Worsened symptoms	13	3 (23.1)	10 (77.0)	
Recent fall	13	5 (38.5)	8 (61.5)	
Multiple sclerosis	N	Yes n (%)	No n (%)	
New or worsened symptoms	4	2 (50.0)	2 (50.0)	

Abbreviation: TIA, transient ischemic attack.

^aTotal N = 367.

panic buying, binge-watching media outlets, negative intrusive thoughts, and nightmares.^{3,26,27} A clinically relevant number of patients answered questions affirmatively with regards to new or worsening depression (27.6%), anxiety (38.3%), sleep difficulties (37.4%), along with negative health consequences, such as a decrease in exercise (36.0%) and changes in body weight (29.5%) during the period of March to May 2020. Similarly, a 20–40% prevalence of anxiety and depression symptoms related to the COVID-19 pandemic has been reported in surveys from China, Italy, and Spain.^{4,28,29} Associated risk factors reported include imposed isolation, younger age, female gender, excessive pandemic-related media exposure, and medical problems. This survey corroborated the effect of age; patients younger than 65 years reported disturbed sleep more frequently than their elders. They also reported new or worsening depression and anxiety more frequently, but this finding was not statistically significant.

Neurologic conditions characterized by acute episodic attacks represented over two-fifths of the survey responders. Patients who experience migraines accounted for 118 of the participants, of which 33% indicated a worsening of their headache frequency or severity. For patients with seizures or epilepsy, 35% reported 1 or more seizures in the weeks before their appointments. This percentage is similar to the proportion of patients with epilepsy reported in the literature who cannot achieve seizure freedom despite receiving anti-seizure medication.³⁰ Data on baseline seizure frequency for these patients is not available, so it cannot be determined if this finding represents increased seizure frequency. Significant stress levels are known triggers for both migraine and epilepsy; depressive symptoms are also associated with poor adherence to medical regimens; unrelenting migraine headaches or prolonged seizures are well-known reasons for emergency room (ER) visits.^{31–34} Minimizing ER visits serves a dual purpose of decreasing the risk of contagion for the patient and decreasing the patient load on an already overburdened system.

Neurodegenerative conditions represented fewer survey respondents, with Alzheimer's disease accounting for 24 patients and Parkinson's disease for 13 patients. Although the numbers are small, more than one-third of patients with Alzheimer's disease or Parkinson's disease reported worsening symptoms. Of the patients with Parkinson's disease, 38.5% surveyed experienced a recent fall, the leading cause of fatal and nonfatal injuries in people older than 65 years.³⁵ Recent studies have shown worsening neuropsychiatric symptoms (eg, agitation, apathy, and aberrant motor activity) in patients with dementia during COVID-19 pandemic mandatory home confinement.³⁶ A survey of 38 patients with Parkinson's disease showed a statistically significant decline of physical activity compared to pre-lockdown levels; patients also experienced worse stress, depression, and anxiety.³⁷

Limitations

This study cannot establish a direct causal relationship between the COVID-19 pandemic and changes investigated in this survey. However, survey questions were framed to ask patients to compare their current experiences to their experiences before March 2020, when the government interventions to prevent the spread of COVID-19 began. This data thus represents the patient's perception of the impact of the COVID-19 pandemic. This study only included patients who completed either a traditional or virtual visit at HPN during the survey period. People more significantly impacted by a loss of employment, loss of health insurance or changes to physical and mental health may not be well represented as they may not be able to attend appointments. Thus, this survey may underestimate changes during this period, and the generalizability of the results is limited. Nevertheless, the health and well-being of patients during this time may still be explored, and future studies will yield longitudinal results to provide more insight.

Conclusions

This survey provides important insights into patients' perception of changes to their health and lifestyle during the early months of the COVID-19 pandemic, aiding providers in implementing practice processes for quality improvement. This study suggests that patients with neurological conditions are susceptible to the psychological effects of a pandemic and strict public health strategies. Thus, it is important to actively screen patients for depression, anxiety, sleep disturbance, and adherence to treatment plans. Many surveyed patients reported worsening symptoms of their neurologic condition. Treatment plans need to include strategies to minimize symptom exacerbations and injuries, resulting in unnecessary hospital ER visits (eg, optimizing drug therapies, use of at-home rescue medications, and regular exercise and sleep routines). Increased utilization of telemedicine may improve access to health care and be already widely accepted by survey participants. The option for patients to have telemedicine follow-ups should be maintained after the pandemic.

Conflict of Interest

None of the authors identify a conflict of interest.

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