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# Understanding patient experiences with epilepsy monitoring during the COVID-19 pandemic

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BOSTON UNIVERSITY  
SCHOOL OF MEDICINE

Thesis

**UNDERSTANDING PATIENT EXPERIENCES WITH EPILEPSY  
MONITORING DURING THE COVID-19 PANDEMIC**

by

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B.S., Emmanuel College, 2019

Submitted in partial fulfillment of the  
requirements for the degree of  
Master of Science

2021

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## **DEDICATION**

I would like to dedicate this work to my former Nursing Director, Susan J. Gordon, DNP, RN, CNRN. Thank you for opening the door to Neuroscience.

**UNDERSTANDING PATIENT EXPERIENCES WITH EPILEPSY  
MONITORING DURING THE COVID-19 PANDEMIC**

**BRIANNA BAILEY**

**ABSTRACT**

**Background:** Epilepsy monitoring units (EMUs) provide a safe environment for forming a more illustrative understanding of the patient's seizure disorder. Patients are admitted to EMUs usually for several days at a time. Upon admission, electroencephalogram (EEG) electrodes are placed and patients are continuously watched via EEG, video, and audio means. By weaning patients off anti-epileptic medications and monitoring brain activity with EEGs, the data will typically allow for a stronger appreciation of the seizure activity. Therefore, it will provide information to develop a more targeted clinical approach for the patient.

**Objective:** The purpose of the study is to gain a better understanding of patients' expectations and experiences with being monitored for seizure activity in an EMU, especially during the Coronavirus Disease 2019 (COVID-19) pandemic

**Methods:** Patients were interviewed with regards to their inpatient EMU admission for continuous EEG monitoring at Beth Israel Deaconess Medical Center (BIDMC). Phone interviews were conducted both before and after the EMU admission for each patient, using a structured questionnaire that focused on topics such as proclaimed knowledge of personal seizure disorder, quality of life, EMU experience, and hospital admission during the COVID-19 pandemic. Patient responses were documented and analyzed in an

exploratory manner to identify relevant themes. The study was conducted according to a protocol approved by the BIDMC Committee on Clinical Investigations.

**Results:** From September 2020 through December 2020, 15 patients were enrolled and interviewed (11 female; age range 26-68 years [median 48]; length of stay range 2-12 days [median 5]). The majority of the population was admitted for event capture or seizure characterization (13/15) and had a history of seizure activity (14/15). The majority of patients had a history of focal seizures (12). Only 4/15 patients had a family history of seizures. Overall, patients felt extremely comfortable speaking with providers. A third (4/12) did not have any notable negative experiences. There were no overarching patterns to the negative experiences that were reported; most responses were specific to the individual. The vast majority (83.3%) applauded providers and staff involved in their EMU admission.

**Conclusions:** Despite the COVID-19 pandemic, epilepsy patients had mostly positive experiences with their EMU hospitalization at BIDMC. Continuous EEG monitoring remains an important aspect of clinical epilepsy evaluation for some patients, and was a feasible and well-tolerated procedure even during pandemic-altered circumstances.

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## LIST OF ABBREVIATIONS

AED	Antiepileptic drug
BIDMC	Beth Israel Deaconess Medical Center
COVID-19	Coronavirus Disease 2019
EEG	Electroencephalogram
EMU	Epilepsy Monitoring Unit
GABA	Gamma-aminobutyric acid
GABA-T	Gamma-aminobutyric acid transaminase
PHI	Personal Health Information
PPE	Personal Protective Equipment

## INTRODUCTION

Epilepsy is most often characterized by visible seizure activity. Seizures are merely a symptom of epilepsy. Rather, epilepsy is better defined as a dynamic disorder. Seizure activity itself is clinically defined by atypical hypersynchronous discharge of a network of cortical neurons. Isolated seizures, non-epileptic seizures, are traditionally triggered by acute systemic or neurological insult. Therapy for isolated seizures is defined by the direct cause of the seizure and does not warrant epileptic interventions like antiepileptic drugs (AEDs) (Bromfield 2006). For example, severe hypoglycemia may result in an isolated seizure. The response would be to treat the hypoglycemia which will indirectly stop further seizure activity (England 2012).

Epileptic seizures differ in that the cause cannot be traced to a source, labeling these seizures as spontaneous. General seizure activity qualifies as epileptic if there are two unprovoked seizures outside of 24 hours. Epilepsy is a spectrum of disorders presenting in over 25 different forms. The disorder can be categorized by seizure type and syndromes. Seizures may be excessive neuronal discharges that are widespread or focused. The type of seizure is determined to be focal, where it is limited to one hemisphere, or generalized, where it crosses hemispheres (England 2012).

A single seizure usually lasts between seconds to minutes without requiring medical intervention. Status epilepticus is an extreme seizure activity which is characterized by prolonged seizing without recovering from the postictal state in between episodes. The individual will remain in this state for more than five minutes and require medical intervention to halt the hyperexcitability (England 2012). Hyperexcitability may

result from several different sources. Bromfield et. al (2006) categorizes the causes by, “increased excitatory synaptic neurotransmission, decreased inhibitory neurotransmission, an alteration in voltage gated ion channels, or an alteration of intra- or extracellular ion concentrations in favor of membrane depolarization.”

Within the cerebral cortex exists two main types of cells. The principal neuron cells are responsible for projecting information to neurons of distant areas in the brain. These cells are commonly excitatory synapses on postsynaptic neurons. Interneurons function within local-circuit cells, where they are able to direct activity of neighboring neurons. These cells are commonly inhibitory synapses on principal neurons or other inhibitory neurons. Activity of principal neuron cells and interneurons are regulated by recurrent inhibition, which acts as part of negative feedback loops (Bromfield 2006).

Acute complications of epilepsy result from the possible collapse and uncontrolled movement throughout the body. Collapse from seizing is uncontrolled and frequently will result in trauma to the head or other parts of the body. This depends on where and how the individual falls. Other acute injuries include biting down on the tongue and/or lip. Complications of chronic seizures may result in cognitive deficits, mental illness, and co-occurrence of somatic diseases such as sleep disorders, migraines, or cardiovascular disease (England 2012). The comorbidities associated with epilepsy are more impactful on the health of the individual than the physical seizure itself. Psychiatric comorbidities are heavily focused on by clinicians, for epileptic patients are twice as likely to develop major depressive disorder compared to others. In response, traditional therapies for depression are taken such as cognitive behavioral therapy and antidepressant

pharmaceuticals. The exact correlation between epilepsy and risk of depression is not well described. Therefore, the comorbidity of depression is treated directly. Other comorbidities include complications in general physical health and reproductive health (Chang 2020).

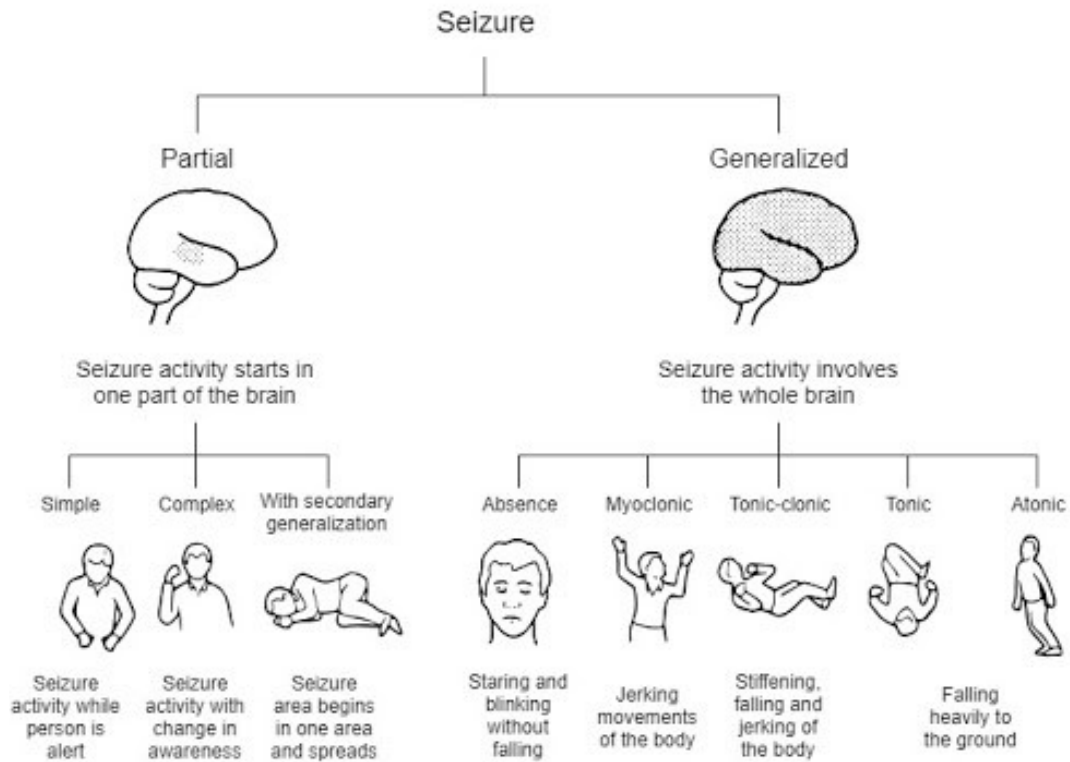
### **Types of Seizures**

The physical manifestation of a seizure is not a disease. Rather, it is the symptom of dysregulated neurological activity. Collectively, epileptic episodes are associated with three main features. This includes an aura, which is a sensation that acts as a warning sign right before the onset of a seizure. Common auras present as visual changes, an odor, or a noise. A second feature is loss of consciousness. This occurs on a spectrum as an individual may have a fixed gaze or completely collapse. The third feature is the motor component. This can vary from lip smacking, to general shaking, to violent convulsions. Both focal and generalized seizure have these three features. However, the specifics vary by the type of seizure activity.

Epileptic seizures are classified into two major types. Although a patient may predominantly experience a specific type of seizure activity, this does not limit the patient from experiencing other types of seizures. Partial (or focal) seizures describe seizure activity originating from one cerebral hemisphere. This is further classified by consciousness and generalized convulsions. Simple partial seizures do not involve an impairment of consciousness, whereas complex partial seizures do. Partial seizures may

evolve to secondary generalized seizures, which involve seizure activity progressing across the hemispheres (Panayiotopoulos 2005).

Generalized seizures describe seizure activity occurring across both hemispheres. Primarily generalized seizure activity begins bilateral. Conversely, secondarily generalized seizures begin in a localized area a partial seizure. Generalized seizures are further described by uncontrolled muscle movements. Absence seizures are generalized seizures that begin with a staring spell and are most common in adolescents. Children typically grow out of these seizures and do not need continued medical management into adulthood. Atonic seizures are more abrupt and associated with a sudden drop in muscle tone. Myoclonic seizures are associated with sudden uncontrolled jolting movements. This results from an increase in muscle tone. Tonic seizures involve muscle stiffening and a loss of consciousness. Clonic seizures include muscle spasms and jerk movements. Tonic and clonic seizure activity may be experienced together as a generalized tonic-clonic seizure, or grand mal seizure (Panayiotopoulos 2005).



**Figure 1: Illustrations of physical manifestations of seizure activity.** Seizure activity and seizure symptoms are defined by two major categories, partial and generalized. These categories are further subdivided based on the three features of seizures, aura, loss of consciousness, and the motor component (emDOCs).

### GABA Receptors

The GABA<sub>A</sub> receptor is a transmembrane receptor composed of five subunits. The subunits come together in a circular fashion forming around a central pore. It is an ionotropic receptor that serves as a ligand-gated ion channel to the inhibitory neurotransmitter gamma-aminobutyric acid (GABA). Within the cell, GABA acts in an inhibitory mechanism to prevent action potentials from firing within the neuron. This is valuable when neurons are overexcited, such as with anxiety. When this system is unable to function appropriately. Without GABA, neurons can be over excited and fire

uncontrollably. Depending on the location, this can result in anxiety and epilepsy (Farb 2014).

GABA<sub>B</sub> receptors are linked to G-proteins, formed by seven transmembrane domains. Instead of creating a pore, like GABA<sub>A</sub> receptors, they use secondary messenger systems via G-proteins to carry out their messages. GABA<sub>B</sub> receptors are predominantly found in the prefrontal cortex where they regulate higher order thinking. GABA<sub>B</sub> receptors act very slowly to inhibit the secondary messenger system associated with adenylate cyclase. Consequently, this reduces the amount of GABA released since the adenylate cyclase cascade is halted. GABA<sub>B</sub> receptors are located presynaptically where they function as autoreceptors to regulate release of neurotransmitters including GABA and post synaptically where they regulate activity of downstream neurons. GABA<sub>B</sub> receptors function by two means, autoreceptors and heteroreceptors. Autoreceptors regulate the release of GABA. By this mechanism, the GABA<sub>B</sub> receptor inhibits the adenylate cyclase cascade of the G-protein. Thus, GABA release is reduced. Heteroreceptors inhibit the protein kinase C cascade of the G-protein which instead inhibits release of neurotransmitters other than GABA (Farb 2014).

### **Pharmacological Interventions**

The therapeutic goal of AEDs is to control seizures in a patient. Unfortunately, AEDs do not cure epilepsy, but they do bring balance to the inherent instability of the brain during seizure activity. When developing a pharmacological plan for patients, the focus is to find a drug therapy or combination therapy that results in the greatest

compliance and the greatest quality of life. In epileptic patients, the neuronal activity is viewed as dysregulated plasticity. The focus pharmacologic therapeutics is to restore balance of inhibition and excitation. A large fraction of patients have seizure disorders linked to genetic mutations in the GABA receptors. Therefore, most AEDs attempt to balance the excitatory neurotransmitters, like glutamate, with the inhibitory neurotransmitters, like GABA (Rogawski 2004).

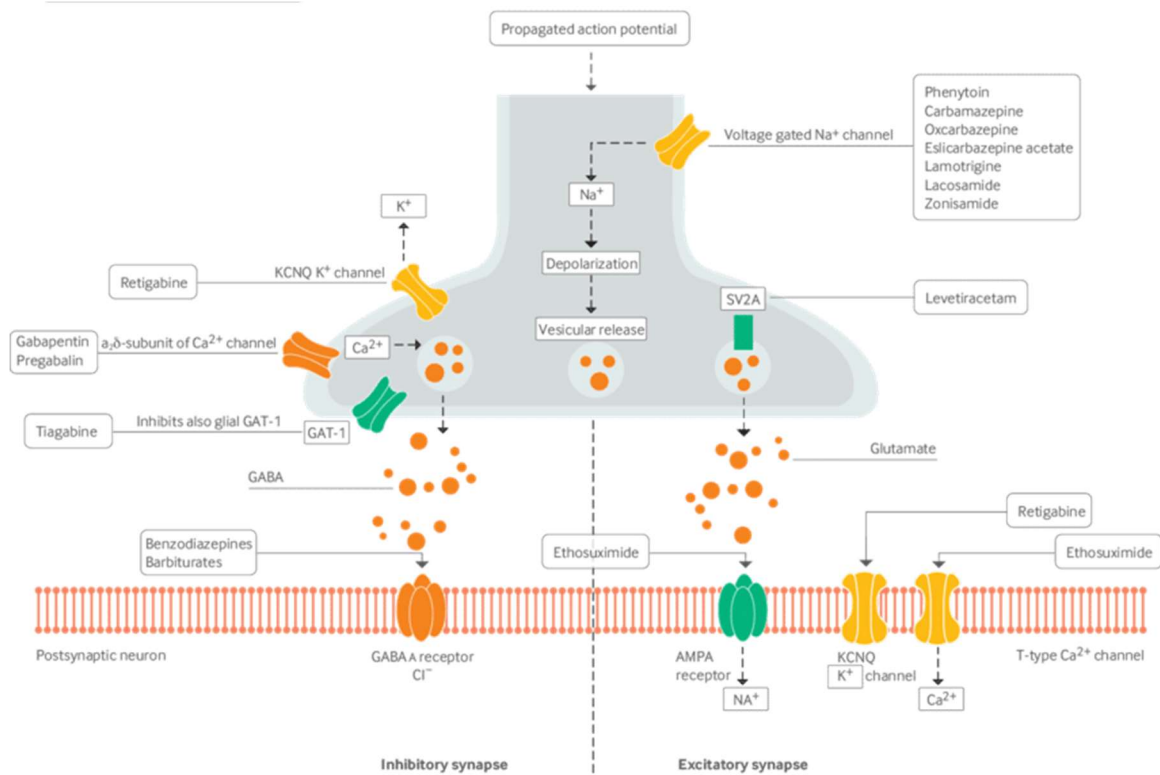
The mechanism of action of AEDs can be broken down into three classes (Figure 2). One class of drugs restores balance by increasing GABA transmission. Vigabatrin is a GABA analogue which inhibits the breakdown of GABA. This occurs by irreversibly inhibiting GABA transaminase (GABA-T), the enzyme responsible for GABA breakdown. This therapeutic has a long half-life and does not induce p450 enzymes. Therefore, it is ideal for patients receiving polypharmaceutical therapy. The p450 enzymes are a major class of enzymes involved in Phase I biotransformation of pharmaceuticals. Valproate is a reversible GABA-T inhibitory and is the drug of choice for myoclonic seizures in adolescents. However, valproate is known to affect other parts of the body such as inhibiting histone deacetylase. As well, it is associated with hepatotoxicity and is biotransformed by glucuronide conjugation. Therefore, it is impacted by the p450 enzymes and is not always ideal for polypharmacy. Tiagabine is an alternative agent for partial epilepsy. It functions as a selective GABA reuptake inhibitor, thereby causing more GABA to remain in the synapse. By consequence, it lengthens the effects of GABA. Common side effects include confusion, difficulty speaking clearly, and mild sedation. It is also metabolized by p450 enzymes and may not

be ideal in combination with other drugs. Topiramate is an alternative agent for generalized and partial seizures. It is known to work at multiple receptors resulting in increased GABAergic transmission and a decreased glutamate transmission. Excitatory glutamate pathways have decreased activity due to topiramate blocking voltage-gated sodium channels, thus increasing the refractory period between synapses. Levetiracetam is commonly used for myoclonic epilepsy. It is highly selective and is not dependent on the p450 enzymes for metabolism (Rogawski 2004). GABA transmission is enhanced by promoting the fusing of vesicles to the membrane of the postsynaptic terminal to then be released into the synaptic cleft.

A second class of AEDs reduce seizure activity by blocking voltage-gated sodium channels. As a result, action potentials are blocked or delayed by a longer refractory period. Common genetic mutations resulting in epilepsy cause the shortening of the inactivation state of action potentials. These drugs work to correct this imbalance. For example, phenytoin slows the rate of recovery of sodium channels, thus lengthen the refractory period. It is predominately prescribed for tonic-clonic seizure activity, but also is an alternative drug for partial seizures. Carbamazepine has the same mechanism of action as phenytoin, but is ideal for partial seizures. It is used as an alternative for tonic-clonic seizures. Lamotrigine is known to inactivate sodium channels. It is commonly prescribed for partial and myoclonic seizures. Compliance is typically high with this drug, as it is not metabolized in the liver. Therefore, patients do not need routine blood monitoring. A small percent of users experience a life-threatening skin rash. In patients of Asian ancestry, the risk of developing this rash is ten times higher. As well, this risk is

seen to be higher with generic forms of lamotrigine. Valproate is also included in this class as it prolongs sodium channel activation in addition to acting as a reversible GABA-T inhibitory (Rogawski 2004).

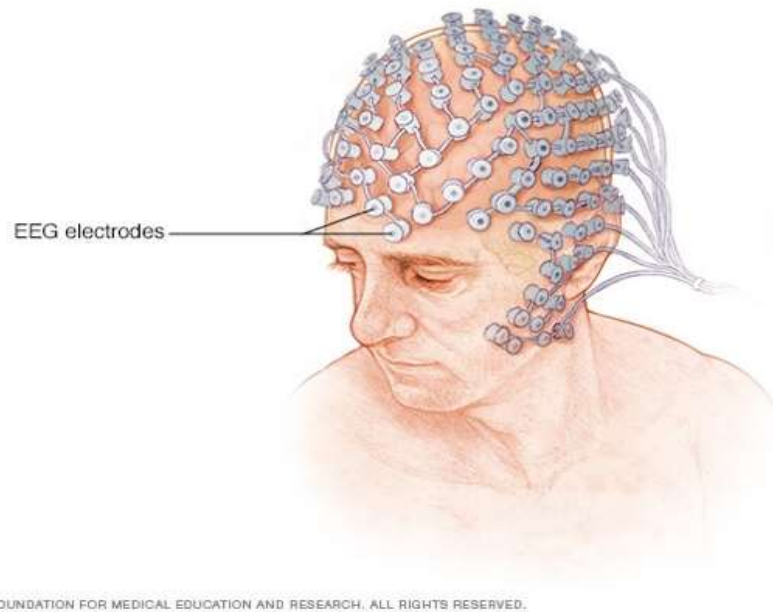
A third class of AEDs primarily function by reducing calcium flow through t-type channels. These channels are found in the thalamus. Dysfunction of calcium t-type channels is characteristic of absence seizures. Absence seizures are a type of generalized epilepsy common in children and are often outgrown. Seizure activity is generated by burst firing of action potentials that are the result of low-frequency stimulation of the midline thalamic structures. Valproate is also included in this class, as it is known to inhibit t-type channels. Ethosuximide also inhibits t-type calcium channels and is frequently prescribed to children with absence seizures. It has a very long half-life of 53 hours, making it easier for this population to comply. Also, it lacks hepatotoxicity. However, 80% of ethosuximide undergoes hepatic metabolism (Rogawski 2004). Nevertheless, the benefits outweigh the costs and is the drug of choice for pediatrics with absence epilepsy.



**Figure 2: Summary of target sites of various AEDs.** Synaptic transmission is initiated by an action potential. To begin, the voltage-gated sodium open and the cell depolarizes. As a consequence of the action potential, the vesicles full of neurotransmitters are released. The vesicle binds to the cell membrane and releases the neurotransmitters into the synaptic cleft. The neurotransmitter then binds to the associated receptor on the postsynaptic membrane. GABAergic, inhibitory, transmission is depicted on the left. Glutaminergic, excitatory, transmission is depicted on the right (Schmidt 2014). Calcium t-type channels are not depicted in the image. These are specific to the thalamus.

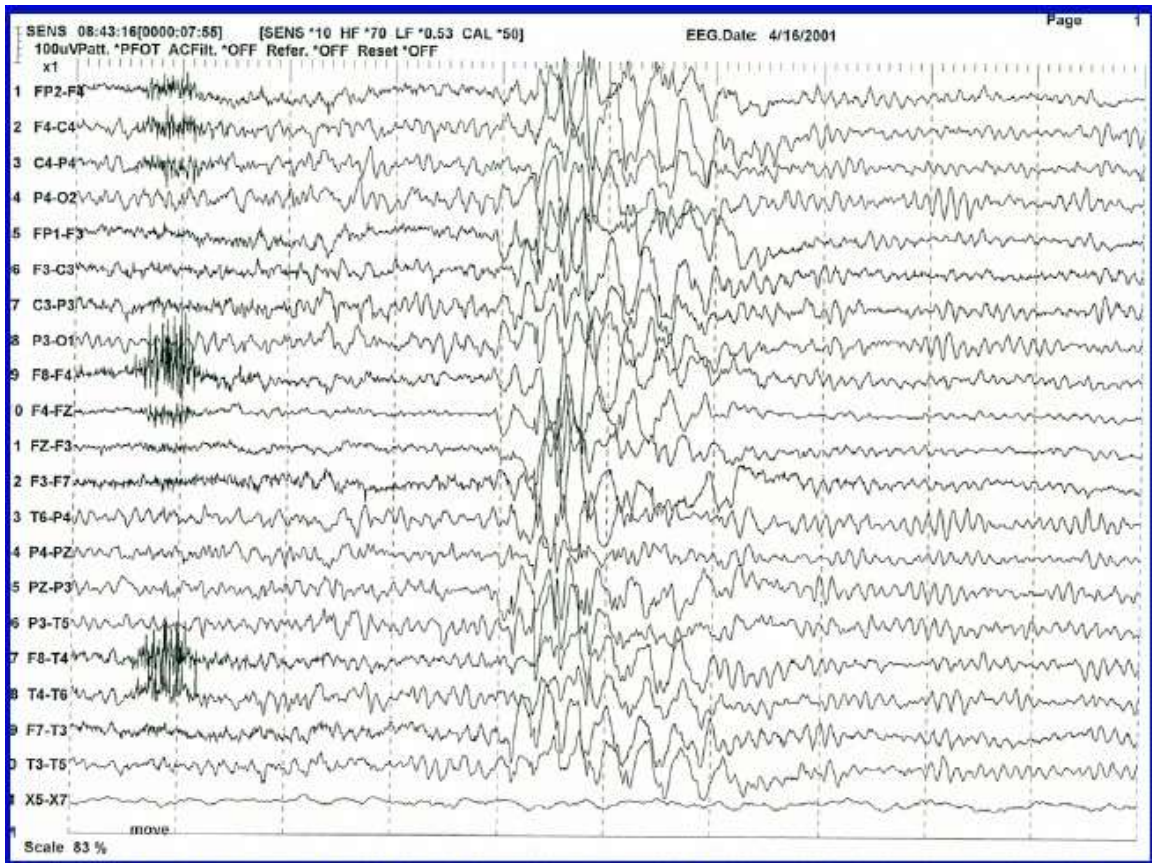
### Electroencephalography

Electroencephalography (EEG) is used to monitor the electrical activity of the brain. It is an external device composed of either plastic or metal electrodes. These are placed directly onto the scalp by a salty paste for conducting electric signals (Figure 3).



**Figure 3: Electroencephalogram electrodes.** Noninvasive EEG electrodes are placed directly on the scalp based on a specific pattern around anatomical landmarks. These plastic or metal discs are precisely placed and usually attached with paste (Mayo Clinic).

The fundamentals of EEG records are based on measuring the electrical-potential difference between two points on the surface of the scalp (Vander 1990). The electrodes send the electrical impulses detected in the brain to a recording machine. These impulses are translated into visual wave patterns which can then be analyzed by a clinician (Freeman 2012). Seizure activity appears as distinct spikes in the wave pattern with high amplitudes, as depicted in Figure 3 (Vander 1990). Monitoring often includes video and audio recording to record any outward indicators of seizure activity. EEG is effective in diagnosing, monitoring, and managing seizure activity (Kulkarni 2013). Monitoring in this way is regularly used due to noninvasive recording, high temporal resolution, and relatively inexpensive (Freeman 2012).



**Figure 3: EEG recording of generalized spikes.** In a generalized seizure, spike wave discharges present on the EEG recording. These are seen in the middle of the image, where the waves have notably large amplitudes. Spike-wave complexes are caused by simultaneous active spread across the cortical areas (Bromfield 2006).

### **Mental Health Comorbidities**

Mental health conditions are historically one of the most common comorbidities associated with epilepsy. These conditions frequently include depression, anxiety, attention deficit hyperactivity disorder, and psychosis. Initially thought to be a side effect of AEDs, mental health comorbidities were linked to the challenges of daily life with epilepsy. Individuals with epilepsy often report their medical condition as very impactful to their quality of life. Further research has revealed a bidirectional linkage between

epilepsy and mental health conditions. An individual with one puts them at greater risk for developing the other. In the case of depression, it has been found to lower the seizure threshold, thus putting the individual at a higher risk for developing epilepsy. Conversely, individuals with poor prognosis of seizures or limited control over seizure activity, are found to be at a higher risk for depression (England 2012).

### **Epilepsy Monitoring Units**

Epilepsy monitoring units (EMUs) provide a safe environment for forming a more illustrative understanding of the patient's seizure disorder. Patients are admitted to EMUs usually for several days at a time. Upon admission, EEG electrodes are placed and patients are continuously watched via EEG, video, and audio means. By weaning patients off anti-epileptic medications and monitoring brain activity with EEGs, the data will typically allow for a stronger appreciation of the seizure activity. Therefore, it will provide information to develop a more targeted clinical approach for the patient.

### **COVID-19**

Originating in Wuhan China, the 2019 novel coronavirus hit the United States in late December 2019. As the Coronavirus Disease 2019 (COVID-19) progressed to a pandemic, countries around the world began to shut down. On March 10th, 2020, Massachusetts officially declared a state of emergency. As a result, all elective procedures were canceled, including video-EEG monitoring in EMUs. Starting in late June 2020, the EMU opened up and patients were being admitted for this procedure. As

the pandemic continued to go on, it has brought much concern to patients and families.

Thus, making it all the more valuable to study patient experiences during this time.

## **SPECIFIC AIMS**

Epilepsy monitoring units (EMUs) are frequently seen in teaching hospitals. They allow for a unique hospital experience where patients are withdrawn from anti-epileptic medications and monitored via continuous EEG, video, and audio means. At Beth Israel Deaconess Medical Center (BIDMC) in Boston, MA, the EMU exists on Farr 11 with a traditional frequency of about 3-4 patients per week. The use of EMUs and outcomes are well described. However, the expectations and experiences from the patient's perspective are not. The purpose of the study is to gain a better understanding of patient experiences with regards to seizure disorders, specifically patients in the EMU. This procedure/testing is performed outside of the context of the study. From this population, interactions with patients will be limited to mail, email, and phone surveys.

Conduction of the study will be occurring in the midst of the COVID-19 pandemic, and therefore will be a major focus when surveying this population. Patients will be surveyed before hospital admission and after discharge, to develop a qualitative analysis. The experience of the patient will be described by his/her:

- Proclaimed knowledge of personal seizure disorder
- Quality of life
- EMU experience
- Hospital admission during the COVID-19 pandemic

## **METHODS**

### **Study Design**

Patients were initially contacted by mail, providing an overview of the study and requesting consent to part take. This occurred after the initial scheduling of an EMU admission - about 1-2 weeks before. Interested patients that responded to the letter were scheduled for an audio call using the application, Starleaf. The initial survey occurred before admission and would last 30-45 minutes. 7 days after discharge home, patients were contacted by email and/or phone to schedule a follow up audio call. The second survey would last about 20-30 minutes.

Initial prospective agreement will be assumed when patients reply to the initial letter expressing interest in participating in the study. At this point, the investigator performed a medical record review. This will include collecting information about:

Patient demographics

Seizure history and clinical characteristics

Related medications

Related history i.e. Previous TBI

Reason for admission to EMU

Past visits to EMU

### **Study population and eligibility criteria**

Epilepsy can present very differently from patient to patient. The EMU population is the target of this study to provide a stronger degree of comparison. All

patients will have been followed and evaluated by BIDMC and be admitted to the same EMU. Although the specifics of the seizure disorder and outcomes of the study will differ from patient to patient, the population will have a relatively consistent experience in exploration of their personal seizure disorders. This study will not be limited outside of the described population parameters with regards to age, sex, race/ethnicity, occupation status, education, etc.

### **Statistical Considerations**

The general framework of this study seeks to explore patient experiences in the EMU. The question format of the surveys is designed to be open-ended. This is to allow for a qualitative evaluation once a reasonable sample size has been reached. The objectives of data analysis aim to describe the demographics of the sample, describe and explain relationships, describe individual experiences, and to define group norms.

This study is largely exploratory and descriptive, though our results will allow for future studies to address these critical questions in a more quantitative manner. We do plan to assess quantitatively the changes in participants' responses from before their EMU admission to after their EMU admission, in a paired-sample manner. Fisher exact or chi-square tests will be used to compare categorical variables and outcomes (such as responses recorded on Likert-type scales). Paired t-tests, multifactor ANOVA, or non-parametric tests will be used for continuous variables (such as seizure frequency).

### **Possible Benefits**

The findings of this study will predominantly help with improving the EMU to better suit the needs of patients and serve as a means of quality improvement. In addition, this will be the first opportunity to study elective monitoring by these means during a pandemic. Establishing a baseline of patient experiences now will allow for more effective quality improvement studies later on. In addition, it is anticipated that this will be one of the first studies interviewing this population during the COVID-19 pandemic. From this, it is intended to propagate further research related to the pandemic.

For the patients participating, this study provides an opportunity to ask questions and learn more about the EMU than they otherwise would. As well, it will allow for quality improvement for future EMU admissions and of other patients admitted to the EMU.

### **Possible Risks and Analysis of Risk/Benefit Ratio**

The risk of this study is minimal. Personal health information (PHI) will be used throughout the study. However, subjects will be de-identified once data analysis begins. Potential areas of risk include psychological effects as a result of survey questions potentially triggering a negative memory or experience. The survey questions have been designed to be open-ended and generalized, allowing patients the opportunity to share only the information that they choose to. As well, a potential concern of the initial survey is that questioning may increase concerns, such as elective hospital admission during the

COVID-19 pandemic. Outside of these potential risks, this is a non-invasive study performed over the phone

### **Recruitment and Consent Procedures**

Patients that are scheduled for observation in the EMU will be contacted by mail before their hospital admission. For patients who are not followed by the Primary Investigator, an email will be sent to the primary neurologist for approval to recruit the patient (Appendix A). The letter will describe the study and ask for a response to set up a phone meeting via Starleaf (Appendix B). No other patients with epilepsy will be recruited outside of this defined population. Consent will be assumed for patients who respond to the recruitment letter, volunteering to participate in the study. Prospective agreement will be formally secured when scheduling the phone surveys, as well as at the beginning of both surveys (Appendix C). Survey questions are designed to be open-ended and non-bias. Patients will be at liberty to disclose as much or as little information as they choose, as well as decline to answer any questions or requests to elaborate.

## RESULTS

The 15 patients involved in this study were predominantly female (11/15). Age on admission ranged from 26 to 68 years with a median age of 48 years. The length of stay for patients ranged from 2 to 12 days with a median of 5 days. The majority of the population was admitted for event capture or seizure characterization (13/15) with a history of seizure activity (14/15). Patients were also admitted for medication adjustments (3/15) and other, atypical reasons (2/15). The majority of patients experienced focal seizures (12). Tonic-clonic seizures were the most common generalized seizure type in the sample (8/15), with patients also experiencing tonic seizures (1/15), clonic seizures (1/15), and myoclonic seizures (1/15). With respect to all seizure types, about half of patients identified known triggers (8/15) and the majority of patients reported experiencing auras (9/15). Only a fraction of patients had a family history of seizures (4/15). Within this group, other common comorbidities included hypertension (5/15) and anxiety/depression (6/15).

In order to analyze patient experiences quantitatively, most questions were asked on a ranking scale. The scales varied from descriptive responses (1 to 5) and numerical responses (1 to 10). The exact scale varied from question, but not between the same questions in the initial survey and follow-up survey. In evaluating descriptive statistics, average values were rounded to the nearest whole number. The various scales are described in presented with the questionnaires in Appendix D and E. Of the 15 patients in the sample, not all answered every question. For questions that not all patients answered, the actual number is listed in Tables 1 through 4, below.

### Proclaimed knowledge of personal seizure disorder

Patients were asked to rank their understanding of their seizure disorder both before and after their EMU admission. The ranking system was scaled by the following descriptions: very poor (1), poor (2), fair (3), good (4), excellent (5). With respect to the individual, the null hypothesis was rejected as there was a statistically significant change in response (critical value: 2.160, t value: 2.639). Of the sample, 50% (7/14) had no change in response, 42.9% (6/14) increased ranking, and 7.1% (1/14) decreased ranking. On the same scale, patients were asked to rank their understanding of their current treatment regimen, before and after their EMU admission. Again, the null hypothesis was rejected (critical value: 2.160, t value: 2.818), where 57.1% (8/14) patients did not change their response, 28.6% (4/14) increased, and 14.3% (2/14) decreased their ranking.

Survey Responses - Proclaimed knowledge of personal seizure disorder					
Topic	EMU admission	Mean	SD	Mode	Median
Understanding of seizure disorder (n = 14)	Before	Fair (3.33)	1.18	Fair (3)	Fair (3)
	After	Good (4.14)	0.95	Excellent (5)	Good (4)
Understanding of treatment regimen (n = 14)	Before	Good (3.93)	0.96	Good (4)	Good (4)
	After	Good (4)	0.78	Good (4)	Good (4)

**Table 1: Survey responses related to questions about knowledge of seizure disorder.** Patients were asked to rank their understanding before admission to the EMU, then again after discharge.

## Quality of life

Survey Responses - Quality of life				
Topic	Mean	SD	Mode	Median
Impact of seizure disorder on daily life	Often (3.6)	1.24	Always (5)	Often (4)
Impact of AED side effects	Rarely (2.36)	1.55	Never (1)	Rarely (2)

**Table 2: Survey responses related to questions about quality of life.** Prior to admission, patients were asked to rank their quality of life.

## EMU experience

Patients were asked to rank their comfort level of speaking with providers both before and after their EMU admission. The ranking system was on the scale of 1 to 10, with 1 being not comfortable at all and 10 being extremely comfortable. With respect to the individual, the null hypothesis was accepted as there was not a statistically significant change in response (critical value: 2.160, t value: 1.729). Of the sample, 78.6% (11/14) had no change in response, 21.4% (3/14) increased ranking, and no patients decreased ranking. On the same scale, patients were asked to rank their control over their treatment plan, before and after their EMU admission. Conversely, the null hypothesis was rejected (critical value: 2.160, t value: 3.489), where 29.4% (5/14) patients did not change their response, 50% (7/14) increased, and 14.3% (2/14) decreased their ranking.

Survey Responses - EMU experience					
Topic	EMU admission	Mean	SD	Mode	Median
Comfort level speaking with providers (n = 14)	Before	9.27	2.47	10	8
	After	9.57	1.16	10	10
Control over treatment plan (n = 14)	Before	7.47	2.47	10	8
	After	8.71	1.64	10	10
Concern about upcoming admission		4.8	3.57	1	4
Was the process worth it		8.85	1.57	10	10

**Table 3: Survey responses related to questions about EMU experience.** Patients were asked a series of questions before admission of their expectations of the EMU. Proceeding discharge, patients were asked the same or similar questions to measure change in responses. In addition, patients were asked to rank their concerns about being admitted to the EMU. Following discharge, patients were asked if the process was worth it.

### Hospital admission during the COVID-19 pandemic

In reference to the COVID-19 pandemic, patients were asked to rank their concern about receiving in-patient medical care on a scale of on a scale of 1 to 10, with 1 being not concerned at all and 10 being extremely concerned. With respect to the individual, the null hypothesis was rejected as there was a statistically significant change in response (critical value: 2.179, t value: 3.203). Of the sample, 46.2% (6/13) had no change in response, 38.5% (5/13) increased ranking, and 15.4% (2/13) decreased ranking. Patients were also asked to rank the impact of the limitation of visitors on a scale of 1 to 10, with 1 being not at all impactful and 10 being extremely impactful. With respect to the individual, the null hypothesis was rejected as there was a statistically significant change in response (critical value: 2.179, t value: 2.936). Of the sample, 38.5% (5/13)

had no change in response, 23.1% (3/13) increased ranking, and 38.5% (5/13) decreased ranking.

Proceeding, patients were asked to rank the importance of the increase in personal protective equipment (PPE) of patients and providers on a scale of not at all (1), slightly (2), moderately (3), very (4), or extremely (5). With respect to the individual, the null hypothesis was rejected as there was a statistically significant change in response (critical value: 2.179, t value: 2.422). Of the sample, 61.5% (8/13) had no change in response, 30.1% (4/13) increased ranking, and 7.7% (1/13) decreased ranking. Lastly, patients were asked to rank how informed they were about how the pandemic would affect their hospital stay on the same scale. With respect to the individual, the null hypothesis was rejected as there was a statistically significant change in response (critical value: 2.201, t value: 2.491). Of the sample, 58.3% (7/12) had no change in response, 33.3% (4/12) increased ranking, and 8.3% (1/12) decreased ranking.

Survey Responses - Hospital admission during the COVID-19 pandemic					
Topic	EMU Admission	Mean	SD	Mode	Median
Impact of COVID-19 on daily life		Moderate (3.73)	1.49	Severe (5)	Moderate (4)
Impact of COVID-19 on seizure disorder		Very mild (2.33)	1.45	Not at all (1)	Very mild (2)
Concern about receiving in-patient medical care during the pandemic (n = 13)	Before	4.07	3.06	1	4
	After	4.69	3.64	1	5
Limitations on visitors (n = 13)	Before	5.4	4	1	6
	After	5.23	3.83	1	5
Importance of increase in PPE (n = 13)	Before	Very (4.2)	0.94	Extremely (5)	Very (4)
	After	Extremely (4.62)	0.77	Extremely (5)	Extremely (5)
Informed about COVID-19		Very (4.33)	0.82	Extremely (5)	Extremely (5)
Informed about impact of COVID-19 on admission (n = 12)	Before	Moderate (3.4)	1.12	Very (4)	Very (4)
	After	Very (3.92)	1.08	Very (4)	Very (4)
How well BIDMC minimized exposure to COVID-19		Above standards (4)	1.08	Far above standards (5)	Above standards (4)

**Table 4: Survey response related to questions about in-patient care during the COVID-19 pandemic.** Before admission, patients were asked to rank the impact of the pandemic on their life as well as to managing their seizure disorder. Also, Patients were asked a series of questions before admission of their expectations of in-patient care during the pandemic. Proceeding discharge, patients were asked the same or similar questions to measure change in responses. As a concluding question, patients were asked to rank how well BIDMC minimized their exposure to COVID-19.

## **DISCUSSION**

The use of EMUs and outcomes are well described. However, the expectations and experiences from the patient's perspective are not. The purpose of the study is to gain a better understanding of patient experiences with regards to seizure disorders, specifically patients in the EMU.

### **Proclaimed knowledge of personal seizure disorder**

On average, patients initially described their understanding of their seizure disorder as "fair". After discharge from the EMU, the average response increased their response to "good." With an overall increase, there was a statistically significant increase on the individual level, with 42.86% (6/14) increasing their answer. More specifically, patients described their understanding of their treatment regimen as "good." Although there was not a significant change in overall response, 28.57 (4/14) patients increased their response. All patients reported a physician as their main source of information for their seizure disorder, with 40% (6/15) performing additional research.

### **Quality of Life**

This population described the impact of their seizure disorder on daily life to be "often." However, there was an overall low impact of side effects from AEDS. In reflection of their life collectively, 60% (9/15) of patients reported independence as a major challenge in living with a seizure disorder. Included were remarks about not being able to drive and regularly being dependent on others. In addition, 40% (6/15) identified

the symptoms of seizure disorders to be a major challenge. Common symptoms reported were fatigue, weakness, dizziness, and poor memory. However, 73.3% (11/15) spoke of significant positive impacts on their life as a whole. Recurrent themes in patient responses were taking better care of self, overall a stronger person, and gained a greater appreciation for life. About a fourth of the patients did not have any positive outcomes to report from their experiences.

### **EMU experience**

Overall, patients felt extremely comfortable speaking with providers. There was not a statistically significant change at the individual level, nor as a group. The average response was 9.27 out of 10 prior to admission, and 9.57 proceeding discharge.

Contrastingly, there was a significant change with reported control of the patient's treatment plan, with 50% (7/14) increasing their response. On a scale of 1 to 10, with 1 being not at all in control and 10 being completely in control, patients reported an average of 7.47 before admission. This increased to an average of 8.71 after discharge from the EMU. When asked about the upcoming admission to the EMU, patients reported an intermediate degree of concern. On a scale of 1 to 10, with 1 being not concerned at all and 10 being extremely concerned, the average response was 4.8.

Only 26.7% (4/15) of patients had previously been admitted to the EMU before. Of those who had not experienced the EMU before, 45.5% (5/11) described their expectations as anticlimactic. Common terms used were boring, relaxing, and quiet. Proceeding discharge, 50% (7/14) of patients still had questions about their seizure

disorder. In reflection of their experience, 33.3% (4/12) of patients declined notable negative experiences. For patients who did report negative experiences, there were no overarching patterns. Rather, most responses were specific to the individual. Conversely, 83.3% (10/12) applauded providers and staff involved in their EMU admission. In addition, 41.7% (5/12) patients expressed their gratitude for their medical treatment and/or overall prognosis. In summary, patients reported that yes, the process was very much worth it. On a scale of 1 to 10, with 1 being not at all and 10 being extremely worth it, the average response was 8.85.

### **Hospital admission during the COVID-19 pandemic**

Of the total population, 86.67% claimed that neither they nor a household member tested positive for COVID-19 prior to admission. On average, patients reported that the pandemic had a moderate effect on their daily life. More specifically, the impact of the pandemic on managing a seizure disorder was described as mild. With regards to receiving in-patient care during the pandemic, patients reported an overall increase in concern. In addition, patients viewed increased PPE as moderately important before their admission to very important after discharge. However, patients responded that the actions BIDMC took, to minimize exposure to COVID-19, were far above standards. As well, the impact of the limitation on visitors decreased proceeding discharge. In general, patients proclaimed to be very informed about COVID-19. Patients responded that they were mildly informed about the impact of COVID-19 on in-patient care, which increased to moderately informed after discharge.

## **Limitations**

Unfortunately, in-patient procedures were limited during the pandemic. It was difficult to recruit patients because the EMU was admitting at about half the rate as before the pandemic. Of the 15 patients, responses to some questions varied greatly. With regards to those topics discussed, the responses do not necessarily represent the entire population. Future research about patient experiences in the EMU should be targeted for when admissions are at the pre-pandemic rate. For future research related to the COVID-19 pandemic, it would be valuable to interview patients from other elective in-patient procedures. Nonetheless, this study serves as an introduction to patient experiences admitted to the EMU during the COVID-19 pandemic.

## **APPENDIX A. Request of approval from primary neurologist to recruit patient**

Hello [name of neurologist],

I hope that you are doing well.

I would like to ask to recruit [name of patient] in a study, conducted by Dr. Bernard Chang, with regards to patient experiences in Epilepsy Monitoring Units (EMUs). Participation in the study will involve two phone surveys, one before admission to the EMU and one after discharge. It will take approximately 30 minutes for the first survey and 20 minutes for the second.

Attached to this email is:

- The recruitment letter

- Survey questions

- An overview of the study

I look forward to hearing from you.

All the best,  
Brianna

## **APPENDIX B. Recruitment letter**

Dear [name of patient],

You are receiving this letter because you are a patient at Beth Israel Deaconess Medical Center (BIDMC). We would like to tell you about a study, conducted by Dr. Bernard Chang, with regards to patient experiences in Epilepsy Monitoring Units (EMUs).

Participation in the study will involve two phone surveys, one before admission to the EMU and one after discharge. It will take approximately 30 minutes for the first survey and 20 minutes for the second. It will not cost you anything to be in the study. If you volunteer to participate, before the first survey we will review your medical records to collect information about your seizure history.

The risks involved in participating in the study include the risk of breach of confidentiality. However, this risk will be minimized by taking the approach steps to securely document necessary personal information behind the BIDMC firewall. We will be documenting minimal personal information as to communicate with you throughout the study. Participating in research is voluntary. Your decision to participate or not participate will not affect the care you receive at BIDMC.

If you have questions about the study and are interested in learning more, or would like to NOT be contacted further about the study, please contact Brianna Bailey by email at [bmbailey@bidmc.harvard.edu](mailto:bmbailey@bidmc.harvard.edu). If we do not hear from you in the next 4-7 days, we will call you to tell you more about the study.

Included in this letter is a description of the study and the list of questions I will be asking if you choose to participate. Thank you for considering our study. I look forward to hearing from you!

All the best,  
Brianna

## **APPENDIX C. Obtaining prospective agreement scripts**

### Scheduling Phone Interview

Thank you for your interest in our research study about patient experiences in Epilepsy Monitoring Units. This study is being conducted by Dr. Bernard Chang at BIDMC and you may contact him at [bchang@bidmc.harvard.edu](mailto:bchang@bidmc.harvard.edu) or 617.632.8930 for more information or if you have any questions about the study or your rights.

The purpose of the study is to gain a better understanding of patient experiences with regards to seizure disorders, specifically patients in the EMU. Conduction of the study will be occurring in the midst of the COVID-19 pandemic, and therefore will be a major focus. You have been invited to participate in this study because of your upcoming admission to the EMU at Beth Israel Deaconess Medical Center.

By volunteering to be in the study, you will be interviewed to learn more about your seizure disorder, quality of life, EMU experiences, and experience being admitted to the hospital during the COVID-19 pandemic. The first interview will last about 30 minutes and the second interview will last about 20 minutes. The interviews will take place over the phone. You can choose not to answer any of the questions you are asked and can stop the interview at any time.

Since you first volunteered for the study, some of your personal information has been collected from your medical records, as described in the initial letter you received. This includes information such as your medical record number, seizure history, related medications, etc. We will keep your answers confidential and will not share personal information about you with anyone outside the research team.

Being in this study is voluntary. Please contact Brianna at [bmbailey@bidmc.harvard.edu](mailto:bmbailey@bidmc.harvard.edu) or at 617.632.8930 with questions about this study. If you have questions about your rights participating in research or would like to speak with someone independent from the research team, please contact the Human Subject Protection Office (617) 975-8500.

### Initial Survey

At this time, would you be willing to answer questions about your health and medical history, as detailed in the letter mailed to you?

I would like to bring to your attention that some of the questions may make you feel uncomfortable. You can stop at any time. You can skip any questions and retract any answers you provide.

I will record your answers in writing, but only collect detailed contact information if you would be willing to participate in the follow-up survey.

The risk of allowing us to record your name with your answers is a loss of confidentiality. We will take reasonable steps to protect the confidentiality of your information.

May I begin?

Follow-up Survey

Thank you for your interest in our research study about patient experiences in Epilepsy Monitoring Units. This study is being conducted by Dr. Bernard Chang at BIDMC and you may contact him at [bchang@bidmc.harvard.edu](mailto:bchang@bidmc.harvard.edu) for more information or if you have any questions about the study or your rights.

At this time, would you be willing to answer questions about your health and medical history, as detailed in the letter mailed to you?

I would like to bring to your attention that some of the questions may make you feel uncomfortable. You can stop at any time. You can skip any questions and retract any answers you provide.

I will record your answers in writing and will be removing any personal identifiable information at the conclusion of this conversation.

May I begin?

## **APPENDIX D. Initial survey**

### Patient education of seizure disorder

How would you describe your understanding of your seizure disorder?

*Very poor, Poor, Fair, Good, or Excellent*

How would you describe your understanding of your current treatment regimen?

*Very poor, Poor, Fair, Good, or Excellent*

What are your main sources of information/education?

### Quality of life

How frequently does your seizure disorder affect your day-to-day life?

*Never, Rarely, Sometimes, Often, or Always*

How frequently do the side effects of anti-epileptic medications affect your day-to-day life?

*Never, Rarely, Sometimes, Often, or Always*

What do you struggle with the most as a result of epilepsy?

What positives came out of this aspect of your life?

### EMU quality control

How comfortable do you feel speaking with healthcare providers and asking questions?

*On a scale of 1 to 10, with 1 being not comfortable at all and 10 being extremely comfortable.*

Do you feel that you have control over your treatment plan?

*On a scale of 1 to 10, with 1 being not at all in control and 10 being completely in control.*

How concerned are you about your upcoming hospital admission in the EMU?

*On a scale of 1 to 10, with 1 being not concerned at all and 10 being extremely concerned.*

For patients staying in the EMU for the first time,

What do you anticipate your hospital stay to be like?

For patients returning to the EMU,

What was/were your past stay(s) in the EMU like?

What do you hope to get out of this process?

### COVID

Have you or a member of your household been diagnosed with COVID?

To what degree has COVID impacted your day-to-day life?

*Not at all, Very mildly, Mildly, Moderately, or Severely*

To what degree has COVID impacted your day-to-day management of your seizure disorder?

*Not at all, Very mildly, Mildly, Moderately, or Severely*

How concerned are you about receiving elective, in-patient medical care during the pandemic?

*On a scale of 1 to 10, with 1 being not concerned at all and 10 being extremely concerned.*

What are your major concerns?

How does the limitation on visitors impact your upcoming admission to the EMU?

*On a scale of 1 to 10, with 1 being not at all and 10 being extremely impactful.*

How important to you is the increase in personal protective equipment of patients and providers?

*Not at all important, Slightly important, Moderate important, Very important, or Extremely important*

To what degree has the delay in elective in-patient epilepsy monitoring affected you?

*Not at all, Very mildly, Mildly, Moderately, or Severely*

How informed are you about COVID-19?

*Not at all informed, Slightly informed, Moderately informed, Very informed, or Extremely informed*

How informed are you about how COVID-19 will affect your hospital stay?

*Not at all informed, Slightly informed, Moderately informed, Very informed, or Extremely informed*

## **APPENDIX E. Follow-up survey**

### Patient education of seizure disorder

How would you describe your understanding of your seizure disorder?

*Very poor, Poor, Fair, Good, or Excellent*

How would you describe your understanding of your prognosis and adjusted treatment regimen?

*Very poor, Poor, Fair, Good, or Excellent*

What questions do you still have?

### EMU quality control

How comfortable do you feel speaking with healthcare providers and asking questions?

*On a scale of 1 to 10, with 1 being not comfortable at all and 10 being extremely comfortable.*

Do you feel that you have control over your treatment plan?

*On a scale of 1 to 10, with 1 being not at all in control and 10 being completely in control.*

What positive experiences did you have during this hospital admission?

What negative experiences did you have during this hospital admission?

Was this process worth it?

*On a scale of 1 to 10, with 1 being not at all and 10 being extremely worth it.*

### COVID

How concerned are you about receiving in-person medical care during the pandemic?

*On a scale of 1 to 10, with 1 being not concerned at all and 10 being extremely concerned.*

What are your major concerns?

How well did BIDMC minimize your risk of exposure to COVID?

*Far below standards, below standards, Meets standards, Above standards, or Far above standards*

How did the limitation on visitors impact your past admission to the EMU?

*On a scale of 1 to 10, with 1 being not at all and 10 being extremely impactful.*

How important to you is the increase in personal protective equipment of patients and providers?

*Not at all important, Slightly important, Moderate important, Very important, or Extremely important*

To what degree has the delay in elective in-patient epilepsy monitoring affected you?

*Not at all, Very mildly, Mildly, Moderately, or Severely*

How informed were you about how COVID-19 will affect your hospital stay?

*Not at all informed, Slightly informed, Moderately informed, Very informed, or Extremely informed*

## **LIST OF JOURNAL ABBREVIATIONS**

AES	American Epilepsy Society
IJPHS	International Journal of Public Health Science
Nat Rev Neurosci	Nature Reviews Neuroscience
Pharmacol Rev	Pharmacological Reviews

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## CURRICULUM VITAE

