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Addressing barriers to surgical evaluation for patients with epilepsy

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ABSTRACT

Objective: Patients with poorly controlled seizures are at elevated risk of epilepsy-related morbidity and mortality. For patients with drug-resistant epilepsy that is focal at onset, epilepsy surgery is the most effective treatment available and offers a 50–80% cure rate. Yet, it is estimated that only 1% of patients with drug-resistant epilepsy undergo surgery in a timely fashion, and delays to surgery completion are considerable. The aim of this study was to increase availability and decrease delay of surgical evaluation at our epilepsy center for patients with drug-resistant epilepsy by removing process barriers.
Methods: For this quality improvement (QI) initiative, we convened a multidisciplinary team to construct a presurgical pathway process map and complete root cause analysis. This inquiry revealed that the current condition allowed patients to proceed through the pathway without centralized oversight. Therefore, we appointed an epilepsy surgery nurse manager, and under her direction, multiple additional process improvement interventions were applied. We then retrospectively compared preintervention (2014–2015) and postintervention (2016–2017) cohorts of patient undergoing the presurgical pathway. The improvement measures were patient throughput and pathway sojourn times. As a balancing measure, we considered the proportion of potentially eligible patients (epilepsy monitoring unit (EMU) admissions) who ultimately completed epilepsy surgery.
Results: Following our intervention, patient throughput was substantially increased for each stage of the presurgical pathway (32%–96% growth). However, patient sojourn times were not improved overall. No difference was observed in the proportion of possible candidates who ultimately completed epilepsy surgery.
Significance: Although process improvement expanded the number of patients who underwent epilepsy surgical evaluation, we experienced concurrent prolongation of the time from pathway initiation to completion. Ongoing improvement cycles will focus on newly identified residual sources of bottleneck and delay.

1. Introduction

While antiepileptic medication is effective in treating seizures for the majority of patients with epilepsy, around one-third of patients will not achieve adequate seizure control with medication alone [1]. For patients with drug-resistant epilepsy that is focal at onset, surgical therapy offers a 50–80% cure rate; surgery can also palliate seizures for some patients with generalized epilepsy [2–4]. However, epilepsy surgery is inadequately offered to patients with drug-resistant seizures [5,6]. Only an estimated 1% of patients with drug-resistant epilepsy undergo surgery in a timely fashion, and there is a 20-year average delay from disease onset to surgical treatment [6–8]. Such delays are not benign for epilepsy surgery candidates, who experience diminished quality of life, unemployment, disability, comorbid psychological disease, and a 0.9% annual risk of sudden unexpected death in epilepsy (SUDEP) [8,9].

Recent growth of epilepsy surgery centers and new advancements in epilepsy surgical techniques have improved outcomes, decreased morbidity, and expanded patient eligibility. Yet, these developments have not led to a parallel increase in the number of therapeutic epilepsy surgeries performed [7]. The basis for this profound underutilization of surgery, despite robust evidence of efficacy and explicit practice guidelines, is multifactorial. Patients' perceptions and physicians' lack of knowledge are hypothesized to play a role [3,10,11]. Access, availability, and processes of care delivery are also potential barriers, as assessment for epilepsy surgery only occurs at specialized centers, and the presurgical workup can be lengthy and burdensome to patients [12,13].

To improve availability of epilepsy surgery at our center, we employed an epilepsy surgery nurse manager to coordinate and expedite the presurgical evaluation of patients with drug-resistant epilepsy.

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This study investigated the impact of our quality improvement (QI) initiative through comparison of preintervention and postintervention patient cohorts.

2. Methods

2.1. Context

The setting for this work is a National Association of Epilepsy Centers (NAEC) Level 4 epilepsy center. As part of an academic medical center, a large proportion of our patients have drug-resistant epilepsy; we also see many patients in consultation for a second opinion on invasive therapies. To ascertain if surgical treatment would be beneficial, patients are referred to our epilepsy monitoring unit (EMU) for prolonged video-electroencephalogram (EEG) monitoring with the goal of capturing multiple seizures. If it is determined from clinical and electrophysiological analysis that surgery may be an option, patients are recommended to complete several additional studies including the following: brain positron emission tomography (PET), neuropsychiatric testing, visual field testing, functional magnetic resonance imaging (MRI) (fMRI), and high-resolution brain MRI (if not already available). The results of these studies are then integrated with the full patient history into a formal case presentation in epilepsy surgery conference, which is attended by epileptologists, neurosurgeons, neuroradiologists, neuropsychologists, nurses, EEG technicians, and administrative staff. In that setting, it is again determined if the patient is a candidate for surgery, and additional testing may be recommended prior to surgical planning, such as Wada testing, single photon emission computed tomography (SPECT), and magnetoencephalography (MEG). Finally, all this information is reviewed; if a surgical intervention is judged to have reasonably high likelihood of benefit and low associated risk, it will be recommended. Possible surgical procedures are the following: intracranial electrode implantation to further inform definitive treatment, lesionectomy, lobectomy, laser ablation, responsive neurostimulator (RNS) placement, and vagal nerve stimulator (VNS) placement. The primary neurologist, the primary neurosurgeon, and the patient determine the final care plan.

2.2. Evaluation

We convened a multidisciplinary team of key stakeholders: physicians, nurses, social workers, and administrative staff from the Division of Epilepsy and the Department of Neurosurgery. This team constructed a detailed presurgical pathway process map and completed a root cause analysis that focused on barriers and sources of delay. Careful evaluation revealed that in the current condition, patients proceeded through the evaluation process without centralized oversight. The steps of the pathway were not readily apparent to patients, physicians, or ancillary care providers. Patients were not clearly identified as participants of the presurgical pathway, and therefore, could be lost to follow-up at some point during the workup. Lastly, multiple barriers to timely scheduling of EMU admissions, outpatient clinic appointments, outpatient studies, and neurosurgical procedures were identified.

2.3. Intervention

Starting in January 2016, an epilepsy surgery nurse manager began coordination of the presurgical pathway. Several changes were then implemented serially: an explicit, sharable presurgical pathway was created and published in Dorsata, a platform for electronic dissemination of care pathways that allows for integration with the medical record (www.dorsata.com) (Fig. 1). A formal tracking system was devised for patients who were discharged from the EMU with the recommendation to be evaluated for surgery. Testing recommendations were routinely clarified and facilitated by the epilepsy surgery nurse manager and fellows. Attention was paid to restructuring the EMU admission process and optimizing EMU bed utilization. Additionally, consultation with the neurosurgeon was coordinated, and the neurosurgical operating room schedule was optimized. Lastly, educational materials were developed for patients (Table 1).

2.4. Measures

We examined three periods of the presurgical pathway process: 1) from initial EMU presurgical admission to presentation in epilepsy surgical conference (stage 1), 2) from epilepsy surgical conference to surgery completion (stage 2), and 3) from initial EMU presurgical admission to surgery completion (full pathway). For each period of the pathway, we measured both patient throughput and sojourn time. For patients with multiple EMU evaluations and/or conference presentations, we counted the first instance of each in which surgery was recommended. In the case of serial surgeries, such as with electrode implantation followed by lobectomy, the first epilepsy surgery date was utilized. We did not assess the percentage of patients completing each step of the pathway as our clinical documentation lacked sufficient detail to determine why patients did not advance toward surgery (e.g., a patient's seizures became well-controlled on antiepileptic medication, a patient decided against an invasive procedure, or a patient's insurance coverage changed), and therefore, we could not accurately specify the denominator. As a balancing metric, we assessed the proportion of all EMU admissions who ultimately completed epilepsy surgery — the goal of our initiative was not simply to perform more surgeries but to perform more indicated surgeries by increasing the number of patients undergoing screening. Lastly, we noted the type of surgery performed: laser ablation, lobectomy/lesionectomy, RNS implantation, VNS implantation, and intracranial electrode implantation (category for patients who did not proceed to a definitive therapeutic procedure within the study timeframe).

2.5. Analysis

We performed a retrospective comparison of preintervention (2014–2015) and postintervention (2016–2017) patients with drug-resistant epilepsy who underwent presurgical evaluation at our epilepsy center. To measure more accurately the impact of our intervention, we limited the cohorts to patients that completed a particular stage within their assigned two-year timeframe (2014–2015 or 2016–2017). For example, a patient who was presented in surgical conference in 2015 and then underwent surgery in 2016 was not included in our analysis. Additionally, patients may have had surgery without participation in this pathway, such as a patient undergoing VNS placement that did not require presentation in surgical conference. Therefore, this study does not represent a comprehensive assessment of all the epilepsy surgery patients at our center from 2014 to 2017.

We used descriptive statistics, the Wilcoxon rank sum test, and the chi-square test to compare patient throughput, sojourn times, and the proportion of patients who were advanced to surgery for the two cohorts. We employed run charts to assess our performance over time and look for evidence of nonrandom improvement with each intervention [14]. Statistical analysis was performed with Stata version 14.0. Statistical significance was defined as $p < 0.05$.

2.6. Ethical considerations

This QI initiative was exempted from institutional review.

3. Results

In total, there were 546 patient admissions (median: 23 per month, interquartile range (IQR): 20–25) to the EMU in the preintervention period and 638 patient admissions (median: 27 per month, IQR: 24–29; $p < 0.001$) in the postintervention period. Not all of these patients were