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Identification of generalized convulsive status epilepticus from emergency medical service records: a validation study of diagnostic coding

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Abstract

Background: Generalized convulsive status epilepticus (GCSE) is a neurologic emergency demanding prehospital identification and treatment. Evaluating real-world practice requires accurately identifying the target population; however, it is unclear whether emergency medical services (EMS) documentation accurately identifies patients with GCSE.

Objective: To evaluate the validity of EMS diagnostic impressions for GCSE

Methods: This was an analysis of electronic medical records of a California county EMS system from 2013 to 2018. We identified all cases with a primary diagnostic impression of "seizure-active," "seizure-post," or "seizure-not otherwise specified (NOS)" and within each diagnostic category, we randomly selected 75 adult and 25 pediatric records. Two authors reviewed the provider narrative of these 300 charts to determine a clinical seizure diagnosis according to prespecified definitions. We calculated a kappa for interrater reliability of the clinical diagnosis. We then calculated the positive predictive value (PPV), sensitivity, and specificity of an EMS diagnosis of "seizure-active" diagnosis for identifying GCSE. Sensitivity and specificity calculations were weighted according to the distribution of seizure cases in the overall population. We performed a descriptive analysis of records with an incorrect EMS diagnosis of GCSE or seizure.

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Access to data

Dr. Guterman had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis

Disclosures of interest

The authors report no relevant conflicts of interest.

Results: Of 38,995 total records for seizure, there were 3401 (8.7%) seizure-active cases, 12,478 (32.0%) seizure-NOS cases, and 23,116 (59.4%) seizure-post cases. An EMS diagnosis of "seizure-active" had a PPV of 65.0% (95% CI 54.8–74.3), sensitivity of 54.6% (95% confidence interval [CI] 39.3–69.0), and specificity of 96.6% (95% CI 95.1–97.6) for capturing GCSE. Limiting the case definition to patients who received an EMS diagnosis of "seizure-active" and were treated with a benzodiazepine increased the PPV (80.2%; 95% CI 69.9–88.2) and specificity (99.3%; 95% CI 98.7–99.6) while the sensitivity decreased (25.1%; 95% CI 17.0–35.3). Across the 300 records reviewed, there were 19 (6.3%) patients who had a non-seizure related diagnosis including non-epileptic spells (7 records), altered mental status (8 records), tremors (2 records), anxiety (1 record), and stroke (1 record).

Conclusions: EMS diagnostic impressions have reasonable PPV and specificity but low sensitivity for GCSE. Improved coding algorithms and training will allow for improved benchmarking, quality improvement, and research about this neurologic emergency.

Keywords

Emergency medical services; prehospital; status epilepticus; seizure; neurologic emergency; coding

INTRODUCTION

Status epilepticus (SE) is a state of abnormally prolonged seizure activity that can lead to neuronal damage and death (1, 2). It is a substantial contributor to worldwide neurologic morbidity and mortality with persistent mortality rates around 15% over the last 30 years (3, 4). First line care for out-of-hospital SE is treatment with benzodiazepines in the prehospital setting by emergency medical services (EMS) providers thus appropriate identification and treatment are crucial and a national EMS priority (5, 6, 7, 8, 9). Evaluating real-world practice patterns relies on accurately identifying the target population, often through review of EMS medical records; however, it is currently unclear whether EMS diagnostic coding accurately categorizes patients with SE. A better understanding of the validity of diagnostic impressions will inform future quality improvement and observational research efforts targeted towards improving SE care nationally.

The EMS medical record system requires EMS providers to record an unstructured written narrative of their assessment and treatment as well as select one or two diagnostic impressions from a prespecified list of possibilities. These impressions enable consistent documentation and allow the identification of particular patient populations for research and quality improvement related to EMS medical care. However, research into the validity of EMS diagnostic coding is limited. Prior attempts to examine the validity of EMS coding for myocardial infarction, stroke, and sepsis have demonstrated poor sensitivity. These data have encouraged quality improvement efforts and have provided a benchmark for understanding EMS practice patterns and identifying important avenues to improve patient care with regard to those conditions (10, 11, 12).

Seizures and SE represent approximately 5% of EMS evaluations and 1% of emergency department visits (13, 14). Despite being a common and morbid neurologic emergency

requiring treatment in the out-of-hospital setting, there have been no studies to date analyzing whether an EMS diagnostic impression of SE is a reliable method for identifying this patient population. The goal of this study is to determine the validity of EMS diagnostic impressions for out-of-hospital generalized convulsive status epilepticus (GCSE) from a single EMS agency.

METHODS

Study Design and Dataset:

We performed an analysis of EMS electronic patient care records (ePCRs) for patients evaluated for out-of-hospital seizure in Alameda County from January 1, 2013 to January 1, 2018. Alameda County is an urban and suburban region with an estimated population of 1.6 million people. The EMS system relies on a fire department-based paramedic first response followed, as needed, by a private paramedic ambulance service or a fire department-based ambulance service.

Patient Population:

Patients with out-of-hospital seizure were identified by EMS diagnostic impressions. Providers select a primary and secondary diagnosis for each patient from a prespecified list of options within the ePCR. We included patients of all ages who had a primary or secondary diagnostic impression of one of the three options used to capture seizure: “seizure-active,” “seizure-post,” and “seizure-not otherwise specified (NOS).”

There were a total of 38,995 records for seizure. We divided records into adult patients (18 years of age and older) and pediatric patients (younger than 18 years old). Using a random number generator, we randomly selected charts for 75 adult patients and 25 pediatric patients who were evaluated for each of the three seizure types, resulting in a total of 300 charts. This study was approved by the institutional review board of the University of California, San Francisco

Study Aim:

The primary goal was to determine the diagnostic accuracy of EMS providers in identifying generalized convulsive status epilepticus (GCSE) among patients being evaluated for out-of-hospital seizure. Secondary goals were to determine whether incorporating information about EMS benzodiazepine administration increased specificity for diagnosing GCSE and to describe the population of patients who received an incorrect EMS diagnosis of status epilepticus and seizure.

Measurements:

Patient age, sex, race, suspicion of alcohol or drug use, and history of epilepsy were abstracted from the chart. We then used chart review as the gold standard for diagnosing seizure type. Four authors (LH, JKS, KAS, ELG) developed definitions to be used in reviewing each patient chart and determining a clinical seizure diagnosis. The definitions grouped patients into the following seizure types: 1) generalized convulsive status epilepticus (narrow definition), 2) generalized convulsive status epilepticus (broad

definition), 3) seizure but not generalized convulsive status epilepticus, and 4) no seizure (Table 1). The narrow definition includes patients who did not regain consciousness between recurrent seizures and is consistent with national guidelines. The broad definition includes patients who may have regained consciousness after their seizure but did not return to their baseline mental status between recurrent seizures, a definition adopted by the Neurocritical Care Society to reflect a more inclusive definition that many are taught, particularly when electroencephalography (EEG) is not available and providers are at risk of missing ongoing subclinical seizures (14).

Two authors (LH, JKS) read every narrative and coded the encounter as one of the four seizure categories (except that a patient who met criteria for GCSE using the narrow definition also met the criteria using the broad definition). We did not identify any additional key words or phrases that would be used to assist the raters in determining the clinical seizure diagnosis through reviewing the narrative. The authors flagged any chart where there was diagnostic uncertainty. A third author (ELG) reviewed any chart that had been flagged for diagnostic uncertainty and any chart where the two initial authors disagreed in their coding. In these cases, the majority diagnosis was used as the clinical diagnosis. There were no cases where all three authors gave a separate diagnosis.

Data Analysis:

We described the baseline characteristics of the study population. We then calculated the sensitivity, specificity, and positive predictive value of the following: 1) diagnostic impression of seizure-active meeting the broad definition of GCSE 2) diagnostic impression of seizure-active meeting the narrow definition of GCSE, and 3) diagnostic impression of seizure-active meeting the narrow definition of GCSE only among patients who received a benzodiazepine. We had used a test-based sampling strategy to identify a set number of records (100 records) within each diagnostic category. By defining the number of records within each category, the sensitivity and specificity calculated from the 300 records which comprised our analytic cohort would not be representative of the true population. To correct for this, we adjusted our calculations according to the distribution of patients with diagnoses of seizure-active, seizure-post, and seizure-NOS in the total population. In order to do this, we calculated the number of records for each diagnosis in the total set of 38,995 patient records for out-of-hospital seizure. We then used these counts to create a table which recorded an adjusted number of adjudicated diagnoses (16). For instance, for patients with active seizures, the adjusted number was the number of active seizure cases in the total population multiplied by the proportion of records in the active seizure group who also received a diagnosis GCSE. We used these new cell counts to calculate a population-adjusted sensitivity and specificity for the 3 seizure-active groups outlined above. To calculate the corresponding 95% confidence intervals, we calculated the sample variance in proportion to the size of the sample group and again adjusted this statistic according to weights that reflected the proportional size of each group of seizure patients. We also calculated an unweighted kappa to measure interrater reliability. Analyses were performed using Microsoft Excel and Stata (Version 15.1, StataCorp, College Station, TX).

RESULTS

Of the 38,995 encounters for out-of-hospital seizure, there were 3,401 (8.7%) records with a diagnosis of “seizure-active,” 23,116 (59.3%) records with a diagnosis of “seizure-post,” and 12,478 (32.0%) records with a diagnosis of “seizure-NOS.” As shown in Figure 1, we randomly selected 100 patients in each diagnostic category. There were two patients who did not have clinical information within the narrative, and they were considered to have a missing clinical diagnosis in the analysis.

Among the 300 records that were reviewed for the validation analysis, patients had a median age of 36.5 years (interquartile range 18–57 years) and there were 133 (44.3%) females. There were no statistically significant differences in age, sex, race, or suspicion of alcohol or drug use (Table 2). There were significantly more patients with a history of epilepsy who received a diagnosis of “seizure-active” and “seizure-post” than “seizure-NOS” ($p < 0.01$). In total, 78 patients met the narrow or broad criteria for GCSE, 201 patients had an out-of-hospital seizure but did not meet criteria for GCSE, and 19 patients did not have seizure. The unweighted kappa for the study investigators was 0.79.

Active Seizure Diagnosis

Of the 100 records with a diagnostic impression of “seizure-active,” there were 65 (65%, 95% confidence interval [CI] 54.8% – 74.3%) who met the broad criteria for GCSE and 56 (56%, 95% CI 45.7%−65.9%) who met the narrow criteria for GCSE, yielding a positive predictive value of 65.0 percent (95% CI 54.8–74.3), sensitivity of 54.6 percent (95% CI 39.3–69.0), and a specificity of 96.6 percent (95% CI 95.1–97.6) for the broad definition for GCSE, and a positive predictive value of 56.6 percent (95% CI 45.7–65.9), sensitivity of 58.5 percent (95% CI 46.6–70.4), and a specificity of 95.9 percent (95% CI 94.3–97.0) for the narrow definition for GCSE.

The diagnostic impression of “seizure-active” was less accurate in adults than pediatric patients with 43 (57.3%, 95% CI 45.4% – 68.7%) adult patients and 22 (88.0%, 95% CI 68.8% – 97.5%) pediatric patients meeting the broad definition of GCSE. Narrowing the case definition to patients with a diagnosis of “seizure-active” who also received benzodiazepines from EMS increased the positive predictive value (80.2%; 95% CI 69.9–88.2) and specificity (99.3%; 95% CI 98.7–99.6) but lowered the sensitivity (25.1%, 95% CI 17.0–35.3).

Of the remaining 35 patients who were given an EMS diagnostic impression of “seizure-active” but did not have GCSE, there was 1 patient did not have a narrative recorded, there were 28 patients who had one or multiple seizures but did not meet criteria for GCSE (15 patients had focal seizures, 8 patients had recurrent seizures with sufficient return to baseline to not qualify as GCSE, and 5 patients were post-ictal), and there were 6 patients who did not have seizures (2 patients had non-epileptic spells, 2 patients had non-specific body tremors, 1 patient was intoxicated, and 1 patient likely had a stroke).

Alternative Seizure Diagnosis

Of the 100 patients coded with “seizure-NOS,” there were 99 patients with narratives recorded. Of these, there were 11 patients (11.1%, 95% CI 5.7% – 19.0%) with GCSE (according to our broad criteria), 82 patients (82.8%, 95% CI 73.9% – 89.7%) with one or multiple seizures that did not meet criteria for GCSE, and 6 patients (6.1%, 95% CI 2.3% – 12.7%) with no seizures (3 patients had non-epileptic spells and 3 patients had non-specific altered mental status and/or presyncopal symptoms).

Of the 100 patients coded with “seizure-post,” there were 92 patients (92%, 95% CI 84.8% – 96.5%) with one or multiple seizures that did not meet criteria for GCSE, 2 patients (2%, 95% CI 0.2% – 7.0%) with GCSE (1 according to narrow criteria and 1 according to broad criteria), and 7 patients (7%, 95% CI 2.9% – 13.9%) without seizure (3 patients with drug or alcohol intoxication, 2 patients had non-epileptic spells, 1 patient had a panic attack, and 1 patient had non-specific altered mental status).

DISCUSSION

In this study of patients evaluated for out-of-hospital seizure, an EMS diagnosis of “seizure-active” had a high specificity, moderate positive predictive value, and low sensitivity for identifying patients with GCSE. Restated, EMS providers use of a diagnostic code for active seizures reflects an accurate diagnosis of GCSE in the majority of cases, however, approximately one third of cases are incorrectly categorized. However, there are many patients with GCSE who are not given a diagnostic impression of active seizures. Limiting the cohort to patients labeled with a diagnosis of “seizure-active” who were given a benzodiazepine improved the positive predictive value of the diagnostic impression to 88% with minimal impact on the specificity but a significant decrease in sensitivity. Overall, the results suggest that using EMS diagnostic impressions can reliably identify a subset of patients with GCSE, although the cohort will be incomplete, which has important implications for future research and quality improvement projects that rely on EMS coding.

Conversely, these data show that an EMS diagnosis of “seizure-post” was effective in excluding patients with GCSE but provided little other useful information regarding presence or absence of seizures more generally. The diagnosis of “seizure-NOS,” by contrast, does not provide useful sensitivity or specificity for accurately ruling in or out GSCE. As its name suggests, it appears to serve as catch-all diagnosis category for presentations that may have some suggestion of seizure on history or exam, and does not appear to be applied in a uniform manner.

To our knowledge, our study is the first attempt to examine EMS coding for patients with seizure and status epilepticus. The findings can serve as a benchmark for future research about out-of-hospital seizure and provide data to guide future efforts to improve EMS coding. Similar analyses of other disease conditions commonly treated by EMS using EMS coding, including stroke and acute pulmonary edema, show similarly limited sensitivity and positive predictive values. One study examining an EMS diagnostic impression of stroke using hospital discharge diagnosis as the gold standard reported a sensitivity of 50% and specificity of 96%, coding performance which was corroborated by a second study

demonstrating a similar sensitivity of 61% and positive predictive value of 77% using a different gold standard (17, 18). EMS diagnostic impressions performed more poorly when identifying acute pulmonary edema, with one analysis demonstrating a sensitivity of only 29% and a positive predictive value of 41% (19). These findings demonstrate clear gaps in the ability of EMS records to accurately capture clinical diagnose and the need for further research and implementation efforts to identify and address the systemic issues contributing to these gaps. Furthermore, these gaps are not limited to EMS. While an analysis of seizure-related codes across emergency department and inpatient encounters demonstrated high sensitivity and specificity for identifying patients with epilepsy, the codes performed more poorly when identifying epilepsy subtypes such as whether a patient had a generalized versus focal seizures (20).

As regards GCSE and seizure, while our study does not explore specific explanations for the inaccuracy of EMS diagnosis impressions, there seem to be at least two potential explanations. First, it may reflect a failure to correctly identify the patient as having status epilepticus in the field. Accurately identifying status epilepticus can be challenging, even for trained epileptologists when seizures are subtle or nonconvulsive (21). However, this failure is more indicative of appropriately identifying seizure activity but failing to delineate the difference between recurrent or prolonged seizure and status epilepticus. Diagnostic inaccuracies may reflect the fact that EMS providers lack extensive neurologic training, have limited time to evaluate their patients, and do not have tools such as EEG to facilitate their diagnostic assessment. If shown to be contributing factors, these barriers can be mitigated with improved training and advances in diagnostic technology, such as extending the use of rapid EEG to the EMS setting similar to the use of electrocardiography for myocardial infarction.

As a second potential explanation, diagnostic inaccuracies may reflect a failure to code appropriately in the medical record despite rendering a correct clinical diagnosis at the time of care (e.g. using a nonspecific seizure diagnosis rather than GCSE despite accurately recognizing status epilepticus). For example, one study examined the validity of seizure-related diagnoses in the emergency department and found that only 30 of 63 (48%) patients with seizures received an accurate seizure-related diagnostic code (22, 23). Failure to use accurate diagnostic codes could be due to multiple reasons. It may be challenging for providers to discriminate between the prespecified diagnostic impressions that are provided in the EMS medical record either because the diagnostic buckets are inherently confusing or because there is insufficient training in the accurate use of the coding system. There may also be personal or system-wide barriers to accurate documentation (e.g. post-hoc documentation or documentation burden).

Our study focused on the experience at a single local EMS agency, which only provides three seizure-related diagnostic options. The definitions of generalized convulsive status epilepticus and the corresponding diagnostic coding systems differ across EMS agencies nationally (24). These different diagnostic codes are matched to a predefined list of diagnostic codes when EMS data is aggregated in the standardized EMS dataset created by the National Emergency Medical Services Information System (NEMSIS). However, the current NEMSIS dataset and certain EMS agencies use the International Classification of

Diseases, 10th Revision (ICD-10) coding system, which incorporates an extensive number of seizure-related diagnoses with information about seizure semiology and etiology that are not relevant to EMS care, challenge trained neurologists in the well-controlled outpatient setting, and may be even more difficult to implement in a standardized fashion by EMS. This complicates the process of matching EMS agency codes to the NEMSIS dataset and subsequently muddles the interpretation of analyses that rely on NEMSIS diagnostic codes to identify study cohorts. A simple, replicable, and clinically relevant framework for EMS coding of seizure would have the opportunity to improve research and quality improvement related to the management of out-of-hospital seizures.

This study has several limitations. It is possible that the sample population is not fully representative of the target population or patients with out-of-hospital seizure nationally. We selected a sample of 100 records within each diagnostic category to ensure all three diagnostic categories were represented and there was an adequate number of adult and pediatric patients. We also examined care for a county in California with broad ethnic and socioeconomic diversity. Regardless, restricting the scope to a single EMS agency and the small size of the analytic cohort limit the generalizability of these results. We also relied on physician chart review of EMS records to provide a clinical diagnosis rather than electrophysiologic data from EEG, in-person examination, or hospital records where documentation is provided by physicians who may have more experience identifying and accurately documenting status epilepticus. The provider narrative may not offer adequate clinical information to make a correct diagnosis and information that the provider missed in evaluating the patient will not be included in the narrative thus relying on EMS records could lead to misclassification and under-ascertainment. The reviewers, however, had a high level of agreement in reviewing the charts, suggesting that the definitions were reliable in categorizing patients. Additionally, in these circumstances, it is more likely that GCSE is underdiagnosed as opposed to overdiagnosed, which would bias our results toward concluding that a diagnosis of active seizures performs worse (lower positive predictive value, specificity, and sensitivity) than it truly performs in practice.

Conclusion

EMS diagnostic impressions have reasonable positive predictive value and specificity but low sensitivity for identifying patients with GCSE. Sampling a broader set of EMS agencies will be important for understanding the generalizability of these findings but our results likely overestimate the performance of EMS diagnoses of status epilepticus nationally given the simple coding system at the agency studied. Improved provider training and simplified, clinically relevant diagnostic codes are potential avenues for improving coding to inform benchmarking, quality improvement, and research efforts related to the management of out-of-hospital GCSE nationally.

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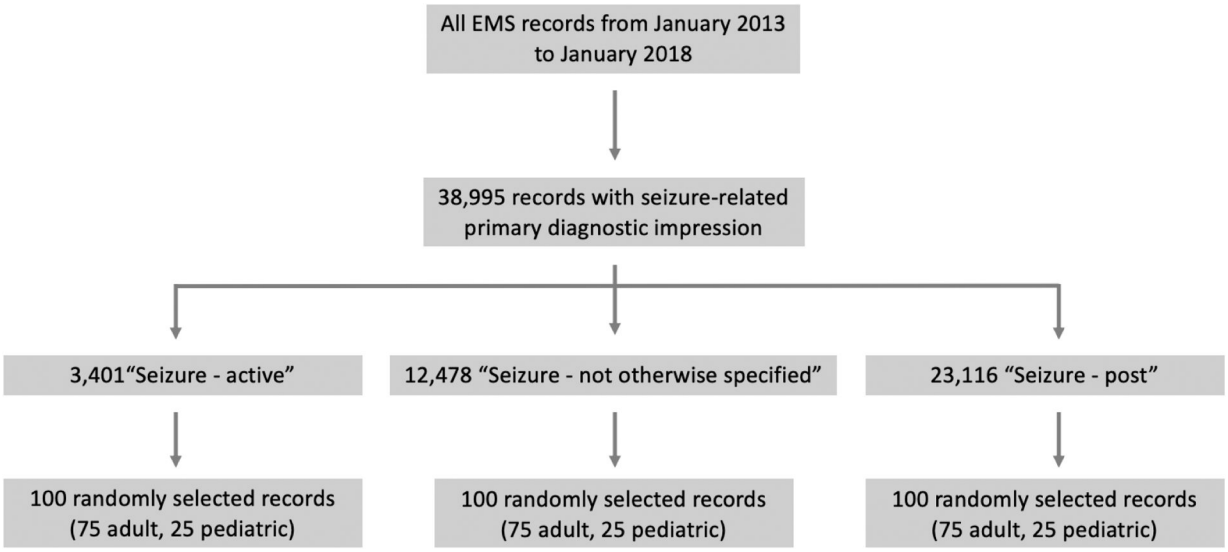

Figure 1. Flow chart of records for out-of-hospital seizure and selection of charts for review

There were 38,995 electronic patient care records were identified for patients with out-of-hospital seizures. Of these 3,401 patients had the diagnostic primary impression "seizure - active," 12,478 had the diagnostic impression "seizure- not otherwise specified," and 23,116 had the diagnostic impression "seizure - post." One hundred charts were selected randomly from each of the three diagnostic impression categories.

Table 1.

Narrative definitions for the clinical diagnosis of out-of-hospital seizure

Diagnosis	Definition
Generalized convulsive status epilepticus (narrow)	• Actively seizing when EMS arrived • Multiple seizures during EMS assessment and narrative states that the patient did not regain consciousness[a] between seizures • Prolonged seizure during EMS assessment either (1) lasting ≥ 5 minutes or (2) lasting < 5 minutes but patient received benzodiazepine before seizure termination
Generalized convulsive status epilepticus (broad)	• Altered level of consciousness when EMS arrived, narrative states suspected or known seizure before arrival, and has seizure during EMS assessment without return to baseline • Multiple seizures during EMS assessment and narrative does not state that the patient returned to baseline (but does return to consciousness)
Seizure but not generalized convulsive status epilepticus	• Altered level of consciousness when EMS arrived and narrative states suspected or known seizure before arrival but no seizure during EMS assessment • Multiple seizures < 5 minutes during EMS assessment and narrative states that the patient returned to baseline between seizures • Single prolonged seizure with spontaneous cessation of convulsive activity in < 5 minutes (i.e. without benzodiazepine administration) with or without regaining consciousness during EMS assessment • Prolonged or recurrent focal seizures
No seizure	• Altered level of consciousness when EMS arrived and narrative does not state suspected or known seizure • “Seizure-like activity” during EMS assessment and narrative states that the movements do not appear to be epileptic

[a]Consciousness was defined according to the Prehospital Treatment of Status Epilepticus (PHTSE) trial as “meaningful speech or obeying commands” (7)

Table 2.

Baseline characteristics of 300 randomly selected records for out-of-hospital seizure according to primary diagnostic impression

	EMS chart diagnostic impression codes			
	Active seizures	**Seizure, not otherwise specified**	**Non-active seizures**	**p-value**
	N = 100	**N = 100**	**N = 100**	
Patient demographic and clinical data				
Age, years, median (IQR)	37.0 (17.5, 60.5)	40.0 (18.0, 57.5)	34.0 (18.0, 54.5)	0.52
Female	50 (50.0%)	45 (45.0%)	38 (38.0%)	0.23
Race				
White	17 (17.0%)	22 (22.0%)	26 (26.0%)	0.51
Black	33 (33.0%)	29 (29.0%)	24 (24.0%)	
Other	50 (50.0%)	49 (49.0%)	50 (50.0%)	
Suspected alcohol and drug use	9 (9.0%)	13 (13.0%)	14 (14.0%)	0.52
History of epilepsy	72 (72.0%)	37 (37.0%)	64 (64.0%)	<0.01
Required respiratory support	36 (36.0%)	11 (11.0%)	4 (4.0%)	<0.01
Adjudicated diagnoses				
Generalized convulsive status epilepticus				
Narrow definition	56 (56%)	9 (9%)	1 (1%)	<0.01
Broad definition	65 (65%)	11 (11%)	2 (2%)	<0.01
Seizure, not GCSE	28 (28%)	82 (82%)	91 (91%)	<0.01
No seizure	6 (6%)	6 (6%)	7 (7%)	0.95

There are three seizure-related primary diagnostic impressions: “seizure-active,” “seizure - not otherwise specified,” and “seizure-post” (labeled non-active seizures above).

IQR: interquartile range; GCSE: generalized convulsive status epilepticus