Patient perceptions of physician-documented quality care in epilepsy

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Lidia M.V.R. Moura [a,*], Thiago S. Carneiro [a], Emily L. Thorn [a], Michael P. Seitz [a], John Hsu [b,c], Andrew J. Cole [a], Barbara G. Vickrey [d], Daniel B. Hoch [a]

[a] Massachusetts General Hospital, Department of Neurology, Boston, United States
[b] Massachusetts General Hospital, Department of Medicine, Mongan Institute, Boston, United States
[c] Department of Health Care Policy, Harvard Medical School, Boston, United States
[d] Icahn School of Medicine at Mount Sinai, Department of Neurology, New York, United States

ABSTRACT

Objective: The aim of this study was to compare physician encounter documentation with patient perceptions of quality of epilepsy care and examine the association between quality and patient assessment of provider communication.
Methods: We identified 505 adult patients with epilepsy aged 18 years or older over a 3-year period in two large academic medical centers. We abstracted individual, clinical, and care measures from 2723 electronic clinical notes written by physicians. We then randomly selected 245 patients for a phone interview. We compared patient perceptions of care with the documented care for several established epilepsy quality measures. We also explored the association of patient's perception of provider communication with provider documentation of key encounter interventions.
Results: There were 88 patients (36%) who completed the interviews. Fifty-seven (24%) refused to participate, and 100 (40%) could not be contacted. Participants and nonparticipants were comparable in their demographic and clinical characteristics; however, participants were more often seen by epilepsy specialists than nonpartici-pants (75% vs. 61.9%, p < 0.01). Quality scores based on patient perceptions differed from those determined by assessing the documentation in the medical record for several quality measures, e.g., documentation of side effects of antiseizure therapy (p = 0.05), safety counseling (p < 0.01), and counseling for women of childbearing potential with epilepsy (McNemar's p = 0.03; intraclass correlation coefficient, ICC = 0.07). There was a significant, positive association between patient-reported counseling during the encounter (e.g., personalized safety counseling) and patient-reported scores of provider communication (p = 0.05).
Conclusions: The association between the patient's recollection of counseling during the visit and his/her positive perception of the provider's communication skills highlights the importance of spending time counseling patients about their epilepsy and not just determining if seizures are controlled.

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1. Introduction

Medical and health policy communities have placed increasing emphasis on quantifying quality of epilepsy care in order to improve outcomes, with particular attention to the inclusion of patient perceptions. The Institute of Medicine highlighted these priorities in their recent annual report [1]. Chief among these priorities is the development and

validation of national performance metrics of care delivery and patient perceptions.

The first approved guidelines from the Physician Consortium for Performance Improvement (PCPI), the Epilepsy Quality Measures (EQM), were published in 2011 by the American Academy of Neurology (AAN) and the American Epilepsy Society [2]. The AAN's Epilepsy Quality Measures address the quality of care as documented by the physician including assessment of seizure frequency, type, etiology, and syndrome; personalized safety counseling; and appropriate referral. These guidelines represent an excellent start but rely exclusively on chart documentation, which may be limited in application to real-world practice. These measures have likewise not been validated against patient perception of care.

In studies of care quality, physician factors such as years of experience, practice setting, and patient characteristics have been associated with EQM adherence by physicians [3–12]. As a result, the AAN's PCPI

* Corresponding author at: Massachusetts General Hospital, 55 Fruit St., Wang 739D, Boston, MA 02114, United States. Tel.:+1 617 726 3311; fax: +1 617 726 9250.
E-mail addresses: lidia.moura@mgh.harvard.edu (L.M.V.R. Moura),
tcarneiro@mgh.harvard.edu (T.S. Carneiro), ethorn@mgh.harvard.edu (E.L. Thorn),
mseitz@mgh.harvard.edu (M.P. Seitz), john.hsu@mgh.harvard.edu (J. Hsu),
cole.andrew@mgh.harvard.edu (A.J. Cole), barbara.vickrey@mssm.edu (B.G. Vickrey),
dhoch@mgh.harvard.edu (D.B. Hoch).

revised the EQM in 2014–2015 [13]. The revised quality measures reinforce the previous measures and increase emphasis on personalized counseling and education [13]. Currently, few published studies have investigated the predictive value of adherence to these revised EQM on outcomes in epilepsy care [14,15]. Increasingly, the patient experience is considered an important aspect of quality and should be cross-validated with physician-based measures of quality [16–20].

In this study, we assessed (1) physician documentation of care provided, including traditional diagnostic or therapeutic decisions and counseling; (2) patients' perceived adherence to quality metrics based on established patient report metrics; and (3) the association between these measures of quality (i.e., quality of care measures vs. patient-reported scores of provider communication).

2. Methods

2.1. Participants, screening, and recruitment procedures

We identified patients receiving care in two major academic medical centers using the Partners Healthcare System Research Patient Data Registry (RPDR). There were 4147 patients aged 18 years or older, seen in an adult outpatient neurology setting, who had at least two visits from June 1st, 2011 to May 31st, 2014 and who received a principal or secondary diagnosis code for epilepsy [ICD-10 code G40 (epilepsy and recurrent seizures) or ICD-9 codes 345.0–345.9 (epilepsy)].

We included patients if they had a confirmed diagnosis of epilepsy, were 18–85 years of age at the time of first visit, had two or more outpatient visits for epilepsy within a maximum interval of 12 months to better assess epilepsy diagnosis and establishment of epilepsy care, had been prescribed antiepileptic drug(s), and had the first visit in the Partners system after July 2011. We chose to exclude patients who had their first visit before 2011, which was the year that the quality measures were implemented, because some quality measures assess the care provided in the first visit. We excluded 3642 patients for the following reasons: 7 (0.2%) were below 18 years old, 41 (1%) were deceased at the time of data abstraction, 1983 (54%) had their first visit in the two major academic medical centers before July of 2011 or after May 31st of 2014, 501 (14%) had less than two visits, 783 (21%) had no epilepsy diagnosis, 306 (8.0%) had been seen by the study investigators (LMVRM, DBH) because they were biased toward higher quality of EQM already, and 21 (1%) had no intervention for epilepsy.

We randomly selected 245 of the 505 eligible patients for a telephone interview (based on the power calculation below). The randomization process consisted of the use of computer-generated random numbers set to select 245 random digits from 1 to 505 inclusive.

We sent the selected subjects a letter (cosigned by their neurologist) describing the study and included an opt-out postcard. After excluding the 57 (23%) of 245 subjects who opted out, we contacted the remaining 188 subjects (76%) to obtain verbal consent, screen for cognitive impairment, and then complete the interview. Treating physicians informed the study team of the presence of cognitive impairment, prior to patient contact. For subjects who had a cognitive impairment based on the treating physician's judgment, we surveyed a proxy that had significant knowledge about the patient when available.

Among the 188 subjects (76%) who did not opt out, we excluded 100 (40%) for the following reasons: the treating neurologist was unreachable or declined participation (37 subjects or 15%), there was cognitive impairment with no proxy available (4 subjects, 1%), the first language was neither English nor Spanish (3 subjects, 1%), and the subject was unreachable by research staff after 3 attempts and 3 voicemail messages (56 subjects, 23%). After these exclusions, there were 88 subjects (36%) who agreed to participate, and 157 (64%) who were excluded. Among the 88 participants, 82 (93%) completed all the questionnaires; 66 patients (75%) had any epilepsy specialist involved in their care; 20 patients (23%) were managed by a general neurologist without epilepsy specialist involvement; and 2 patients (2%) were exclusively treated by

a primary care physician within the study time frame of three years. Participants and nonparticipants were comparable with respect to clinical and demographic characteristics. The Partners Institutional Review Board approved this study protocol.

2.2. Procedures

Two research assistants were trained by the lead investigator (LMVRM) in the standardized abstraction of demographic, provider specialty, and epilepsy quality (EQM) data from electronic medical records. We assessed reliability by comparing three independent reviews of 20 randomly selected medical records. Interrater reliability was substantial (kappa > 0.8) on most measures (i.e., seizure frequency; epilepsy intervention; seizure type, etiology, or epilepsy syndrome; whether the clinician asked about side effects; counseling of women of childbearing age; and consideration of referral to a comprehensive epilepsy center) and moderate (kappa ranging from 0.6 to 0.8) on measures corresponding to personalized epilepsy safety counseling and screening for psychiatric or behavioral health disorders. The lead investigator resolved disagreements.

2.3. Measurements

The main independent variable in this study was quality of care in epilepsy, as defined by the AAN EQM [21]. The epilepsy quality measures were assessed in two ways: (1) physician documentation based on chart abstraction and (2) patient report during phone survey.

2.3.1. Chart abstraction

Each medical record was reviewed in its entirety. The source of demographic information was a centralized registration department, and patient care information was placed in the electronic record by the patient's treating physician. We abstracted demographic data, including age at first visit, gender, primary language, race, education level, type of insurance (private vs. public), medical center, and the involvement of an epilepsy or neurology specialist.

Neurologists with formal, specialized training in epilepsy were considered epilepsy specialists. The background of each neurologist was confirmed on the Partners website (http://www.partners.org/doctors/). All other neurologists were classified as general neurologists. A patient was identified as having subspecialty epilepsy care if seen by an epilepsy specialist at any time during the study time frame.

Abstracted clinical information included age at first seizure, epilepsy diagnosis, seizure frequency, and number of comorbidities. The duration of care was defined as the period between the first visit for epilepsy care and the last visit for epilepsy care between June 2011 and May 2014. Intensity of care was measured as the number of visits for epilepsy care within this time period. New diagnosis of epilepsy was defined as whether the patient was diagnosed and started on an antiepileptic medication within the care period. Seizure frequency was defined as the mean number of seizures during the 6 months prior to the visit. This measure was estimated based on physician documentation of patient-reported frequency, when available. When not available, this information was listed as missing data.

Disease duration was measured as the difference in years from age at first seizure to age at first visit. Baseline history of drug-resistant epilepsy was defined as a failure of adequate trials of two tolerated, appropriately selected and dosed antiepileptic drug schedules to achieve sustained seizure freedom [22].

Abstraction of the data from the medical record was standardized for each EQM (Supplemental Table e1): Seizure frequency documentation (EQM 1-A) was considered complete when seizure frequency was documented at each visit. Epilepsy intervention (EQM 1-B) was considered complete when an epilepsy intervention occurred at all visits where patients did not report being seizure-free. Epilepsy syndrome or etiology (EQM 2) was considered complete when seizure syndrome/etiology

was documented at the first visit. Antiepileptic drug side effects (EQM 3) were considered complete with side effect documentation at each visit. Safety counseling (EQM 4) was considered complete when the physician documented the provision of counseling and education at least once per year. Psychiatric or behavioral symptoms screening (EQM 5) was considered complete when psychiatric or behavioral health disorders were screened at each visit. Women's counseling (EQM 6) was considered exclusively in females of childbearing potential (i.e., ages 18–44 years) and was considered complete when it was documented at least once per year. Referral to a comprehensive epilepsy center (EQM 7) was considered exclusively in patients with medication-refractory seizures and was considered fulfilled when the provider documented a discussion about epilepsy surgery at least once within the study time frame. For patients being seen at a comprehensive epilepsy center already, we searched for evidence of discussing or offering presurgical evaluation in the epilepsy monitoring unit, when appropriate [21].

2.3.2. Phone survey

The survey administered to each patient included a series of questionnaires to measure the following: (a) patient-reported quality, assessed by the AAN's epilepsy quality measures and (b) patient experience, assessed by a subset of the Clinician and Group-Consumer Assessment of Healthcare Providers and Systems Survey (CG-CAHPS) [23].

For patient-reported quality, a telephone interview survey was used to assess items that are part of the epilepsy quality measures [13]. The final tool consisted of seven scored questions regarding the patient perception or recollection of processes of care, with yes or no answers (Table 1 and Supplemental Table e1). For patient experience, the patient-reported perception of provider communication for this study consisted of a subset of Clinician and Group Survey (CG-CAHPS) items that gauged the frequency of communication-related constructs.

Specifically, the questions referred to the care in the 12 months preceding the last office visit based on how often the provider was easy to understand, listened carefully, gave information about health questions and concerns, seemed to know important information about the patient's medical history, showed respect for what the patient had to say, spent enough time with the patient, and discussed the results of ordered exams. Response choices were as follows: never, sometimes, usually, or always. The questionnaire specified that the patient should answer with respect to the physician that provided epilepsy care [23].

2.4. Statistical analysis

The unit of analysis is the point estimate via patient recall of all visits over a 12-month period, and the independent variable was the AAN's EQM adherence at all visits regarding care for epilepsy within the study time frame.

In detail, the EQM total score was calculated as a continuous variable using a proportion of applicable EQM fulfilled, ranging from 0 (no EQM fulfilled) to 1 (all applicable EQM fulfilled), per patient, then averaged.

We also calculated two subscores to better reflect the domains of care: (1) clinical counseling quality and (2) clinical management quality.

The clinical counseling quality continuous score included the assessment of documentation of medication side effects, safety counseling, women's counseling, and psychiatric screening (EQM 3, 4, 5, and 6). The clinical management quality continuous score included the measures of the documentation of seizure frequency, seizure intervention, epilepsy/syndrome, and consideration of surgical intervention (EQM 1A, 1B, 2, and 7).

In addition, we derived a binary measure of defect-free care per patient. Defect-free care was defined as adherence to all applicable EQM [24]. This approach has been widely used in the literature and has excellent sensitivity to interprovider performance variability [15,25].

Table 1
Demographics, care characteristics, and clinical characteristics of eligible patients (N = 245).

Characteristics	Enrolled N = 88	Nonenrolled N = 155	p-Value
	N (%)[a] or mean ± SD		
Demographics			
Age, years	37.8 ± 12.6	40 ± 13.5	0.08
Gender			
Female	45 (51.1)	79 (50.9)	0.97
Male	43 (48.9)	76 (49.1)	
Primary language			
English	82 (94.2)	140 (95.3)	0.74
Others	5 (5.8)	7 (4.8)	
Care characteristics			
Academic medical center			
A	24 (27.3)	58 (37.4)	0.10
B	64 (72.7)	97 (62.6)	
Insurance			
Public	28 (31.8)	52 (33.8)	0.75
Private	60 (68.2)	102 (66.2)	
Specialty provider's involvement[b]			
Epilepsy specialist	66 (75)	96 (61.9)	<0.01
General neurologist	20 (22.7)	58 (37.4)	
Primary care physician	2 (2.3)	1 (0.7)	
Clinical characteristics			
Age at first seizure in years	22.2 ± 14.3	26.5 ± 17	0.07
Disease duration in years	14.3 ± 13.1	13.5 ± 13.5	0.68
Duration of care[c]			
Less than one year	17 (19.3)	26 (16.7)	0.60
At least one year	71 (80.7)	129 (83.3)	
Number of visits	5.2 ± 2.5	5.4 ± 2.5	0.60
New diagnosis of epilepsy	30 (34.1)	45 (29)	0.41
Seizure type			
Simple partial	6 (7.5)	8 (6.7)	0.77
Complex partial	12 (15)	21 (17.4)	
Secondarily generalized	29 (36.3)	32 (26.4)	
Generalized tonic–clonic	24 (30)	43 (35.5)	
Absence	1 (1.3)	3 (2.5)	
Multiple	8 (10)	13 (10.7)	
Other	0 (0)	1 (0.8)	
Number of current antiepileptic drugs			
One	54 (62.8)	96 (61.9)	0.90
Two	21 (24.4)	39 (25.2)	
Three	9 (10.5)	13 (8.4)	
Four	2 (2.3)	5 (3.2)	
Five	0 (0)	1 (0.6)	
Drug-resistant epilepsy[d]	22 (25)	46 (29.8)	0.41
Antiepileptic drug side effects			
Patient denied symptoms	47 (74.6)	89 (73)	0.80
Patient experienced side effects	16 (25.4)	33 (27)	
Number of comorbidities[e]	2.3 ± 2.3	2.8 ± 3.4	0.22
Number of seizures[f]	3 ± 11.4	15.8 ± 80	0.17

[a] Numbers may not sum to totals because of missing data, and column percentages may not sum to 100% because of rounding.
[b] Specialty provider's involvement was categorized according to the highest level of care received during the study time frame: Neurologists with formal subspecialized training in epilepsy were considered epilepsy specialists. All other neurologists were classified as general neurologists.
[c] Duration of care was measured as the number of visits for epilepsy care within the care period. The patients were descriptively grouped as follows: 'less than one year' or 'at least one year' according to the time between the first visit and the last visit for epilepsy care.
[d] Drug-resistant epilepsy was defined as the failure of adequate trials of two tolerated and appropriately selected antiepileptic drug schedules (whether as monotherapies or in combination) to achieve sustained seizure freedom.
[e] The number of comorbidities for each patient was assessed from the medical history or problems list of each patient's electronic medical record and from comorbidities reported by physicians during the chart abstraction process.
[f] The number of seizures represents the mean number of seizures reported during the previous six months of the last visit for epilepsy within the care period. The seizure frequency values were not normally distributed: the median value for seizure frequency was 0 [IQR: 0–2] for both enrolled and nonenrolled patients. The p-value reported in Table 2 refers to a t-test. A two-sample Wilcoxon signed-rank test yielded similar interpretation (p = 0.2).

On the patient-reported perception of provider communication questionnaire, each possible answer was quantified: 'never' was recorded as 0, 'sometimes' as 0.33, 'usually' as 0.66, and 'always' as 1. Then, a summary score was calculated as the average of the scores on

each answer, with 0 corresponding to the lowest possible score and 1, the highest. This approach has prior validated use [16,18,23,26].

We calculated kappa statistics to assess the agreement between the patient-reported and the physician-documented adherence to each epilepsy care quality measure. The intraclass correlation coefficient (ICC) was used to assess the agreement between the continuous measures (i.e., the patient-reported and physician-documented scores). Kappa statistics or ICCs of <0, 0.01–0.20, and 0.21–0.40 are considered poor, slight, and fair agreement, respectively. In a secondary analysis, we used McNemar's tests to compare the paired proportions of quality adherence (physician-documented vs. patient-reported).

We then made bivariate comparisons between patient demographic and clinical variables and measures of care. We used linear regression models to assess the association between physician-documented clinical counseling quality and patient-reported scores of provider communication, as well as the association between patient-reported clinical counseling quality scores and patient-reported scores of provider communication. The statistical analysis also explored potential factors that could affect patient perceptions of care (e.g., care, demographic, and clinical characteristics). In these two academic centers, patients with epilepsy are traditionally seen by general neurologists and/or epilepsy specialists. We performed sensitivity analysis adjusting for type of provider, which was categorized according to the highest level of care received during the study time frame. Neurologists with formal subspecialized training in epilepsy were considered epilepsy specialists, and all other neurologists were classified as general neurologists. We selected this variable for adjustment based on the principle that all patients should receive high quality care. We did not capture additional care for epilepsy that may have been provided outside the system and by other healthcare providers such as social workers and nurse practitioners.

In our study design, we included patients that came to establish care, which we defined as having a first visit for epilepsy care and at least two follow-up visits for epilepsy care within the study time frame. There were 27 patients (31%) that had only a total of 3 visits (1 first visit + 2 FUs), and there were 61 patients (69%) that had more than 3 visits (1 first visit + more than 2 FUs) within the same study time frame.

In an additional exploratory analysis, we measured the proportion of adherence to each of the epilepsy quality measures within the study time frame between the two separate intensity-of-care groups (Supplemental Table e3): (1) patients with ≤3 visits total: a first visit for epilepsy care and one or two follow-up visits within the study time frame, referred to as 'establishment of care' and (2) patients with >3 visits total: a first visit for epilepsy care and more than two follow-up visits within the study time frame, referred to as 'establishment and maintenance of care'. A more detailed description of the criteria for each measure is provided in Supplemental Table e1 and Table 2. A comparison of adherence to quality measures between physician documentation (through chart abstraction process) and patient reporting (through phone survey) was measured with p-values, calculated using chi-square or Fisher exact test when appropriate.

Analyses were conducted using SAS Studio®, version 9.4. This study sample of a total of 88 patients has 90% power to detect a difference in perceptions of quality care adherence of 20%. The threshold for significance was 95% (p-value = 0.05).

3. Results

3.1. Descriptive data

Participants had a mean age of 37.8 ± 12.6 years (Table 1). Fifty-one percent of participants were female, and 94% spoke English as their primary language (Table 1). Eleven of the participants (13%) had proxies complete the surveys on their behalf, and over the study time frame of 2 years, the 88 patients had an average of 6 (SD: 3) visits per patient.

Subjects reported having a mean patient-reported seizure frequency of 7.2 (SD: 26.5) during the six months prior to the last visit for epilepsy within the care period. The most common side effect to antiepileptic drugs was mood alterations, reported by eight patients (12.7%). The differences between the time when patients completed the phone survey and the time of their most recent prior visits had a median of 6 months [IQR: 3.5–12].

The number of seizures is the mean number of seizures reported during the previous six months before the last visit for epilepsy within the care period. In Table 1, the seizure frequency appears to differ between the enrolled and unenrolled (means of every other month vs. one per week), which can be attributed to the nonnormal distribution of seizure frequency: the median value for seizure frequency was 0 [IQR: 0–2] for both enrolled and nonenrolled patients (Table 1). The p-value of 0.17 from a t-test, as reported in Tables 1 and 2, showed +the difference between the groups not to be significant, and

Table 2
Epilepsy quality measures adherence.

Epilepsy quality measure	Agreement and disagreement between physician-documented and patient-reported quality measures			
	Agreement ratio	Disagreement ratio	Kappa statistic	95% CI
1A — Seizure frequency	66/85 (78%)	19/85 (22%)	0.17	[−0.07, 0.42]
1B — Seizure intervention	N/A	N/A	N/A	N/A
2 — Etiology, seizure type, or epilepsy syndrome	55/86 (64%)	31/86 (36%)	<0.01	[−0.18, 0.19]
3 — Querying and/or intervention for side effects of antiseizure therapy	57/85 (67%)	28/85 (33%)	0.08	[−0.13, 0.28]
4 — Personalized epilepsy safety issue and education provided	41/77 (53%)	36/77 (47%)	0.04	[−0.12, 0.19]
5 — Screening for psychiatric or behavioral health disorders	N/A	N/A	N/A	N/A
6 — Counseling for women of childbearing potential with epilepsy	12/23 (52%)	11/23 (48%)	−0.06	[−0.35, 0.23]
7 — Referral to comprehensive epilepsy center	13/17 (76%)	4/17 (24%)	0.20	[−0.31, 0.73]

Table 2 shows the proportion of adherence to each of the epilepsy quality measures within the study time frame with the agreement between the methods of measurement (physician-documented through chart abstraction process vs. patient-reported through phone survey). Question 1 asked whether the provider asked about the number of seizures since the last visit at each encounter, corresponding to EQM-1A in Supplemental Table e1. Question 2 asked whether the provider discussed underlying epilepsy etiology, corresponding to EQM-2. Question 3 asked whether the provider discussed specific epilepsy syndrome, e.g., juvenile myoclonic epilepsy or absence epilepsy, also corresponding to EQM-2. Question 4 asked about provider query of possible medication side effects at each visit, corresponding to EQM-3. Question 5 asked whether the provider discussed nonpharmacological treatments in the last 3 years, corresponding to EQM-7. Question 6 asked whether the provider discussed safety issues related to epilepsy, such as driving restrictions, corresponding to EQM-4. Question 7 asked women whether the provider gave counseling on birth control and family planning (EQM-2 was considered fulfilled if either Question 2 or 3 was answered positively).

a two-sample Wilcoxon signed-rank test yielded the same interpretation (p = 0.2).

3.2. Agreement between physician documentation and patient-reported quality

The mean physician-documented quality overall score was 0.6 (SD: 0.3). The mean clinical counseling score was 0.5 (SD: 0.3), and the mean clinical management score was 0.8 (SD: 0.2). The analog mean patient-reported quality scores were 0.8 (SD: 0.2, quality overall score), 0.8 (SD: 0.3, clinical counseling score), and 0.8 (SD: 0.3, clinical management score).

The clinical management quality measures, e.g., those reflecting seizure frequency, type, and etiology and therapeutic interventions, all exceeded 69% adherence (Table 2). The adherence ranged from 12 to 80% for clinical counseling quality.

There was slight agreement between physician-documented and patient-reported scores on the following: seizure frequency (agreement rate: 78%, disagreement rate: 22%, k: 0.17), querying and/or intervention for side effects of antiseizure therapy (agreement rate: 67%, disagreement rate: 33%, k: 0.08), and personalized safety counseling (agreement rate: 53%, disagreement rate: 47%, k: 0.04) (Table 2). There was no agreement on the following: epilepsy syndrome, etiology, or seizure type (agreement rate: 64%, disagreement rate: 36%, k: <0.01) and counseling for women of childbearing potential (agreement rate: 52%, disagreement rate: 48%, k: −0.06).

By assessing the intraclass correlation coefficient, the agreement between the physician-documented clinical counseling quality scores and patient-reported scores was greater than the agreement with respect to clinical management scores (slight: 0.07 vs. poor: −0.03, respectively).

When compared with physician documentation, patients reported greater care adherence to measures including epilepsy etiology (85% vs. 70%, McNemar's p = 0.02), asking about side effects (85% vs. 71%, p = 0.02), safety counseling (86% vs. 52%, p < 0.01), and women's counseling (87% vs. 57%, p = 0.03). Twelve-and-a-half percent of patients received defect-free care (Fig. 1). The rates of defect-free care per patient are shown in Supplemental Table e1. For Fig. 1, we selected the measures that were applicable to all patients and left out the measures that were applicable to specific patients (with different denominators), for clarity. We report the remaining measures in Table 2 and Supplemental Table e1.
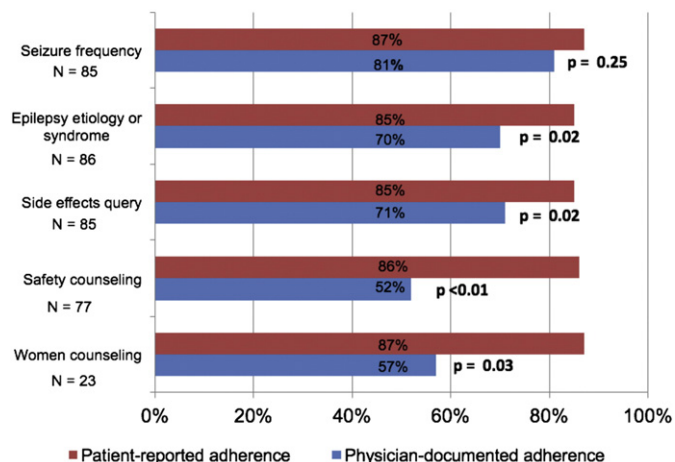
3.3. Epilepsy care quality vs. patient-reported scores of provider communication

The mean patient-reported score of provider communication was 0.9 ± 0.1. Higher patient-reported clinical counseling scores were associated with improved patient-reported scores of provider communication (p = 0.05, Fig. e1). Similar results were found when adjusting for type of provider in the care (p = 0.05).

Linear regression models did not find a significant relationship between physician-documented clinical counseling scores and patient-reported scores of provider communication (Supplemental Table e2).

Exploratory analysis showed that adherence to quality measures among intensity-of-care groups did not significantly differ, as shown in Supplemental Table e3.

4. Discussion

This cross-sectional study examined adherence to the currently accepted epilepsy quality indicators in the care of patients with epilepsy and described differences between the documentation and the patient report of epilepsy care quality. As expected, overall epilepsy quality measure adherence was similar to that of prior studies [4,6–9,11,12,15]. However, there was poor agreement between documentation of counseling and the patient's report of counseling.

Neither relying on documentation nor patient reporting is perfect. The report by a patient that he received counseling or education during a visit might be more reliable than the documentation in the medical chart since such activities are less likely to be recorded even when done. However, we also know that the patient's recollection or comprehension of the encounter is notoriously imperfect [6,7,11]. In fact, it has been reported in a sociolinguistic study of patients with epilepsy that, even immediately following a visit, there is disagreement between the physician and the patient on the content of the consultation [27]. In our study, incongruence between physician and patient reports was found even in clinical measures related to etiology and seizure type, emphasizing potential gaps in patient education and counseling. The discrepancy between these two potential interpretations remains a challenge [17,28]. We believe that, when used together, these methods may be complementary. While our study design was not primarily focused on examining the correlation between chart documentation and patient recollection, our findings highlight this important gap in care.

Measurement of quality through chart abstraction alone is informative. We have verified the accuracy of these measures of quality using a retrospective chart abstraction where the hypothesis that higher quality care is associated with better seizure control was tested. We found that complete adherence to AAN/EQM quality measures (defect-free care) was not associated with either more or less seizure control over the study interval [15]. By adding a second set of metrics focused on the patient's experience, the present study expands our previous observations and begins to develop ways to explore the internal consistency between patient reports of care.

Two kinds of patient perceptions were examined in this study, and the second major finding of this study is that higher patient-reported scores in clinical counseling were associated with higher patient-reported scores of provider communication. This association emerged when evaluating quality care adherence as a continuous variable. Admittedly, it was not present when comparing defect-free care with nondefect-free care which is a more conservative approach. Nevertheless, we believe counseling remains an important part of the development of a model that can predict quality of care.

Accurately measuring the patient experience is also important since it is one of the main objectives in constructing a pay-for-value healthcare system [29–33]. Patient-generated reports of experience with care in epilepsy are quite limited, though validated patient-report scales have been used to measure experience related to specific aspects of epilepsy treatment, such as medication effects [34]. In the

Fig. 1. Proportion of adherence to the epilepsy quality measures. This figure shows the proportion of adherence to each of the epilepsy quality measures within the study time frame. McNemar's test compared the physician-documented and patient-reported quality measures adherence. The sample size (N) varied across quality measures because of missing data or eligibility. The proportion of adherence to each specific epilepsy quality measure is shown in the respective bar.

absence of a validated questionnaire to measure experience with provider communication and care, we adapted and used a subset of the validated Clinician and Group-Consumer Assessment of Healthcare Providers and Systems Survey (CG-CAHPS) that includes this domain [23]. The CG-CAHPS survey tool has been used extensively to assess patient's perception of quality of care and guide healthcare improvement policies [26,35,36].

There are a number of limitations to this study. Most notably, there was a low recruitment rate (36%) from two closely related tertiary care centers, which traditionally see patients with more complicated diagnoses and have prompt availability of specialized care. Our final recruitment rate could have been higher if we had not counted the patients that we could not reach because of inability to get consent from their treating neurologists. We could also have targeted more patients. Although our response rate was comparable with other studies (14–76%), enrolled patients were self-selected which may introduce selection bias toward patients who had a particularly good or bad experience [7,37–39]. In addition, both centers are located in the same urban setting in the northeastern United States, which may provide much different results than in other areas. Specifically, this region has a very high density of neurologists, who might be better informed on practice guidelines compared with primary care physicians who are more likely to be treating epilepsy in other areas. Our results, therefore, would overestimate physician's adherence to quality measures.

Phone surveys present additional limitations. Though informative, they are limited by several factors including recall bias, postevent time interval variations, and fatigue due to the number of questions and due to acquiescence bias (wanting to please the interviewer).

Recall bias is likely, given the questions involved visits over several months. In an attempt to mimic real-world surveys, we asked patients to report the care quality over the previous twelve months. Because of this methodological decision, we were likely close to the surveys that hospitals have been using to report their quality (e.g., CAHPS). However, one should note that our capture of patient perception did not necessarily correspond to all chart-reviewed visits. The time between the most recent patient visit and the phone survey may have impacted patient recall as well as participation. The duration of the survey, about 30 min on average, may also have decreased the accuracy of survey responses because of patient fatigue. In fact, a high rate of surveys were started but stopped before being completed (17%), suggesting that patient fatigue was a significant issue. Accuracy may have been higher if patients were called sooner or immediately after the visit, instead of having a median time difference of 6 months between the visit day and the completion of the survey. However, this study aimed to assess perceptions of quality care in the framework of real-world practices, where a provider's performance is constantly being evaluated by consumer assessment surveys, such as the Clinician and Group-Consumer Assessment of Healthcare Providers and Systems Survey (CG-CAHPS), ordered by the Partners Healthcare System's Quality and Safety initiative department. Typically, Partners Healthcare randomly selects a subset of patients in the system to answer a survey about the visit within 3 to 12 months, asking about the patient's satisfaction to care received over the previous 12 months.

Cognitive impairment is a frequent dilemma in research using phone, web-based, and even in-person interviews. As explained in the Methods section, we screened for cognitive impairment by asking the treating physicians to inform the study team if a patient was cognitively impaired. If so, we would instead survey a proxy for the patient, minimizing the potential confounder. We did not use a specific tool, such as a mini-mental score, to assess cognitive impairment.

In summary, our findings point to serious discrepancies between physician documentation and patient perceptions of care quality. Our study highlights the importance of spending time teaching patients about the various aspects of epilepsy care such as discussions about epilepsy syndrome, etiology, or seizure type, which is critical from the patient perspective. However, these results must be weighed against the demonstrable limitations and barriers surrounding validation of current primary standardized techniques for quality care assessment.

5. Conclusion

This study's findings highlight the existing gap between medical documentation and patient-reported quality of care in epilepsy. The clear association between the patient's recollection of counseling during the visit and his/her positive perception of the provider's communication skills highlights the importance of spending time counseling patients about their epilepsy.

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