Patient awareness of seizures

Article abstract—In 31 consecutive patients who were admitted to an epilepsy monitoring unit, we prospectively determined whether the patients were aware of having seizures. On admission, all patients stated that they knew of at least some of their seizures. Eight of 23 with classifiable epileptic seizures recognized that they were occasionally unaware of their seizures. During telemetry, following full recovery of consciousness after each seizure, we asked the patients whether they had recently had a seizure. For control purposes, we asked the patients the same question at random times. Among patients with seizures, there were no false-positive answers. Only 6 of 23 (26%) of the patients with epilepsy were always aware of their seizures, including complex partial and secondarily generalized events, and 7 of 23 (30%) were never aware of any seizures. Self-reporting of seizures was unreliable: Patients reporting the lowest baseline frequency of seizures had the highest fraction of unrecognized seizures. Seizure awareness was lowest for patients with temporal lobe foci, especially on the left side. Patients with primarily generalized epilepsy were more likely to be aware of tonic-clonic seizures than were patients with secondarily generalized partial seizures. All four patients with nonepileptic attacks believed that they always knew of their seizures, but only three of the four patients actually did always know. Unrecognized seizures are frequent and should be considered in patient management and in studies.

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The traditional office-based approach to seizure management requires the patient to inform the physician of the occurrence of seizures. Therapy is successful when the patient reports having fewer, or no, seizures over an interval of time. This approach assumes that patients are aware of having seizures and are able to maintain accurate counts of seizure frequency. Absence seizures are often not recognized by children, and Kasteleijn-Nolst et al.[1] showed that minor myoclonic seizures induced by photic stimulation may go unrecognized by the patient. Many physicians and nurses assume that while "minor" seizures might occasionally be missed, patients would likely know when they had "major" events; however, the ability of patients to recognize the occurrence of seizures of any type has not been assessed formally. We studied the ability of patients to recognize when a seizure had occurred. Preliminary results were presented in abstract form.[2]

Methods. We prospectively assessed seizure awareness in 31 consecutive, unselected patients who were admitted to an epilepsy monitoring unit. Patients had been referred to the epilepsy center from community physicians because of a lack of seizure control with medical therapy and were admitted for either clarification of diagnosis or presurgical localization. Three patients did not complete the study. On admission to the monitoring unit, patients were given questionnaires (Appendix) by which to assess their self-perception of seizure awareness. We asked patients if they always, sometimes, or never were aware of when their seizures occurred. Family members were also questioned about whether the patient always knew of seizures. EEG/video telemetry was performed using standard techniques.[3] We monitored patients for seizures using patient-initiated push-button alarms, computer-assisted seizure detection (Stellate Systems, Montreal, Canada), and around-the-clock direct nursing observation of video telemetry. Simple partial seizures were not included in this study. For each seizure involving loss of consciousness, hospital staff came to the patient's bedside to ensure safety, the reposition the patient, suction, and administer nasal oxygen as needed. The staff member then left the room when the seizure ended and the patient's clinical condition was judged to be stable. At least 30 min to 1 hr later, after the patient had regained full consciousness (determined by nursing observation of patient behavior on remote video), a staff member entered the room and asked the patient whether he or she had had a seizure recently or whether anything unusual had occurred. At random times during the hospital stay, staff asked the same question as a positive control. All but three patients in the study had neuropsychometric assessment including formal assessment of memory functions. Data were analyzed using GB-STAT version 5 for Windows (New England Software, Greenwich, CT). Associations between discrete variables were assessed using the chi-square test (e.g., seizure type vs. recognized or not recognized). Patient awareness of seizures was calculated as the percentage of seizures the patient recognized having out of all seizures detected by any method during monitoring. Linear regression techniques were used to identify factors predictive of patient awareness.

Results. Of the 31 patients, three did not have seizures or otherwise could not complete this study. Four of the remaining 28 patients had nonepileptic attacks. The diagnosis of epilepsy was confirmed in the remaining 24 patients. One patient had bilateral seizure foci, one side temporal and the other side extratemporal, and was excluded from further analysis because of unclassifiable seizure

Table 1 *Patient characteristics*

Group	n	Age (yr) ± SD	Onset age (yr) ± SD	Females (%)	Patients with hippocampal sclerosis (%)	Patients with infectious etiology (%)	Patients with mass lesion (%)
LT	5	33 ± 8	8 ± 8	60	60	0	0
RT	8	35 ± 13	15 ± 14	44	89	11	11
All T	13	34 ± 11	13 ± 13	50	78	7	7
ET	5	32 ± 13	12 ± 7	60	0	0	20
PG	3	29 ± 8	10 ± 6	100	0	0	0
MF	2	26 ± 13	18 ± 2	50	0	0	0

LT/RT = left/right temporal; T = temporal; ET = extratemporal; PG = primarily generalized; MF = multifocal. Note: Some patients had multiple pathologies.

Table 2 *Survey results*

Group	n	Reported awareness (no. of patients)—said "always knew"	Actual awareness (no. of patients)		Average percentage of seizures of which patients were actually unaware ± SD		
			Knew all Sz	Knew no Sz	T-C	C-P	C-P + T-C
NEA	4	1	0	0	0	NA	
LT	5	3	1	3	100 ± 0	93 ± 12	97 ± 75
RT	8	4	2	4	100 ± 0	53 ± 47	56 ± 47
All T	13	7	3	7	100 ± 0	66 ± 43	71 ± 42
ET	6	5	0	0	75 ± 35	73 ± 41	80 ± 28
PG	3	0	3	0	0	NA	0
MF	2	0	1	0	0	75 ± 0	87 ± 18

Sz = seizure; T-C = tonic-clonic (either primarily or secondarily generalized); C-P = complex partial; NEA = nonepileptic attacks (events listed as "T-C" for convenience); LT = left temporal; RT = right temporal; All T = all temporal (left or right), combines LT and RT; ET = extratemporal, partial onset; PG = primarily generalized; MF = multifocal.

type. Clinical characteristics for the studied patients are summarized in table 1.

The survey results for the remaining 27 patients are summarized in table 2. Overall patient awareness of seizures was very low, with 63% (95% confidence interval [CI], 44 to 81%) of all seizures unrecognized by the patient. Averaging across patients, the average percentage of unrecognized seizures was 61% (95% CI, 42 to 79%). Secondarily generalized tonic-clonic seizures of temporal lobe origin were never recognized as having occurred by the six patients who had them (16 unrecognized convulsions). Seven patients, all with temporal lobe onset, were never aware of any seizures. Only three of 20 patients (15%) with partial onset seizures were always aware of their seizures. Patient age and duration of epilepsy did not correlate with the percentage of unrecognized seizures (regression, $p > 0.3$).

Some types of seizures were more likely to go unrecognized by patients. Primarily generalized tonic-clonic seizures (four seizures in three patients receiving a final diagnosis of primarily generalized epilepsy) were never missed. In contrast, 100% (16/16) of secondarily generalized tonic-clonic seizures of temporal lobe origin went unrecognized by the patient (chi-square = 19.4, $p < 0.0001$). This included several seizures in which the patient perceived the onset of the simple-partial phase and reached to push a warning button to summon the nurse, but subsequently could not recall either the aura or the attempt to summon help. On average, patients with extratemporal foci were aware of their convulsive seizures 75% of the time. Patients with left temporal foci were less likely to recognize their seizures (average 96.7% unrecognized, SD = 75%) than patients with right temporal foci (average 56%, SD = 47%). This was statistically significant (two-tailed t-test, F = 40.9, $p = 0.003$).

Patient perception of self-awareness was poor. In the initial survey, 12 of these patients (10 with partial onset and 2 with primarily generalized epilepsy) believed they were always aware of when their seizures occurred. In contrast, the survey showed that only four of the 12 who thought they always knew did in fact know of all events. Two of these four had primarily generalized epilepsy. Of the 10 patients with partial onset epilepsy who believed they always knew when seizures occurred, only 20% (2/10) actually did always know. Seven patients actually believed they were never aware of major seizures; six of them were correct and the seventh was aware of only one seizure out of five. Several items in the questionnaire were designed to reveal possible occurrences of seizures that the patient had not recognized as seizures: "Do you ever get lost and not know why? Do you ever have unexplained injuries? Do you ever have episodes of confusion other than seizures?" These questions, as well as similar questions directed at family members, were poor predictors of how often a pa-

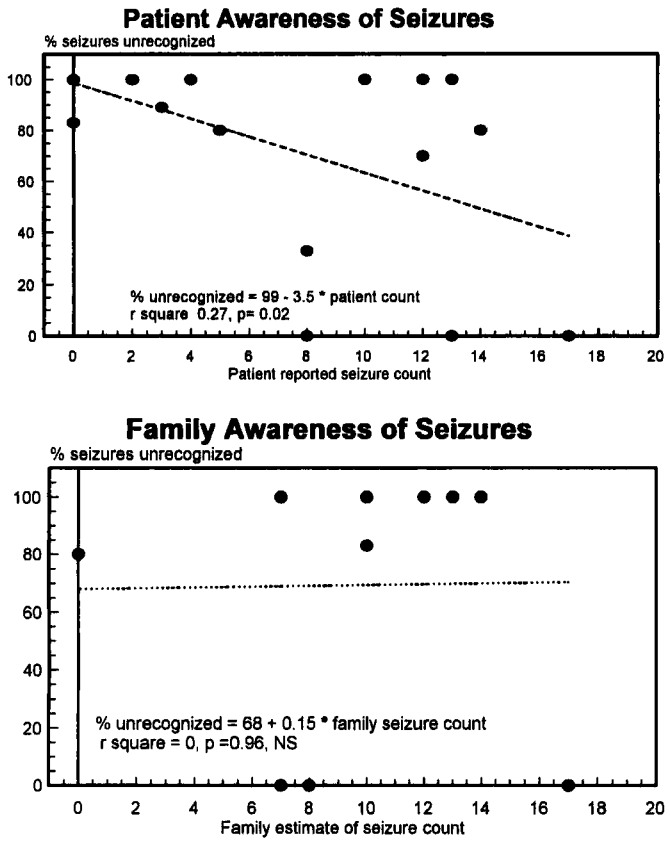

Figure. Patient versus family reporting of seizure frequency. Self-estimates by patients correlated inversely with the likelihood of having unrecognized seizures. Some patients may report lower seizure frequencies because they are unaware of their seizures, rather than as a result of good seizure control. Estimates of seizure frequency obtained from family members do not correlate with unrecognized seizures and may be more reliable in some settings.

tient might be unaware of seizures (multiple ANOVA, not significant with $p = 0.6$).

Awareness of seizures correlates with self-reported seizure frequency in an unexpected way (figure): Patients who reported fewer seizures per month were more likely to be unaware of seizures when they did occur. Two patients who reported manifestly unbelievable monthly seizure frequencies of more than 50 tonic-clonic seizures each were eliminated as outliers. Linear regression showed an inverse correlation between self-reported seizure frequency and the likelihood of being unaware of seizures (correlation coefficient = -0.52, $r^2 = 0.27$, two-tailed $p = 0.027$). On the other hand, family estimates of seizure frequency did not correlate with the degree of self-awareness ($r^2 = 0$, $p = 0.96$).

Seizure awareness did not correlate with the results of memory tests. Immediate and delayed free recall scores of the logical and visual reproduction portions of the Wechsler Memory Scale–Revised did not predict the likelihood of being unable to recall seizures (multiple ANOVA, $p > 0.6$).

Discussion. This study of seizure awareness shows that patients with partial onset epilepsy may not be reliable observers of seizure frequency in some settings. The degree of unawareness may not, however, extend to real life situations. We performed the study in the artificial setting of an epilepsy monitoring unit where external, or environmental, clues were removed. The patients were in bed in a quiet room for most of the time. In daily life, patients are more likely to be told that seizures happen in a variety of ways: a crowd of people suddenly appear, the patients suddenly find themselves in an ambulance or emergency room, or an ongoing activity abruptly seems to change. A key inference of this study is that patients, especially those who have no awareness of seizures, rely on environmental clues. Patients who are home alone may be more prone to underreport true seizure frequency.

Why are patients unaware of seizures? Not as a consequence of fixed memory deficits, which did not correlate with the likelihood of being unaware of seizures. Also, lack of awareness is not due to the convulsive phase of the seizure, since patients with primarily generalized epilepsy were always aware of their seizures. However, among patients with partial onset seizures, awareness was better for nongeneralized than generalized events, indicating a contribution of the intensity of seizures to the mechanism of unawareness. Almost by definition, patients are always aware of simple partial seizures. This agrees with the findings of Schulz et al.,[4] who found that patients were often unable to remember the simple partial phase of their seizures. In that study,[4] with seizures of greater intensity, as measured by EEG spread, patients showed a greater likelihood of forgetting their aura. We hypothesize that the more intense seizure produces a greater degree of postictal confusion and amnesia, and possibly interferes with self-perception. Lack of recollection of seizures can be viewed as Todd's paralysis of the limbic system: The remainder of the brain recovers and the patient awakens before he or she is able to lay down new memory traces.

These results should be incorporated into daily clinical practice. When dealing with patients with localization-related epilepsy, patient self-reports of seizure frequency should be treated, at best, as a minimum seizure count and, at worst, as grossly unreliable. For some patients, self-reporting of seizure counts inversely correlates with actual seizure counts. Some questions might be useful in uncovering seizures that the patient had not recognized as such. The questions we used had a poor discriminant value in this population; however, in the outpatient epilepsy clinic at the Barrow Neurological Institute, it is not rare for patients to deny having recent seizures but to admit to unexplained injuries, episodes of confusion, and occasionally to unexplained motor vehicle accidents.[5] We believe these questions should be asked of all patients with partial epilepsy at each clinic visit, and attempts should be made to gather seizure reports from family members.

Surgical treatment of epilepsy generally requires

recording of several seizures to determine localization. If patients kept in a hospital room do not know about the occurrence of seizures, then methods of detecting events, other than patient self-reporting, must be used. Computer-driven detection of ictal-EEG patterns[6] is useful, but there are seizure types that often do not manifest on surface EEG. The most important of these is frontal lobe epilepsy,[7] but this also occurs with complex partial seizures of temporal lobe origin.[8] Not all epilepsy monitoring units employ 24-hr observers of video telemetry. Units that rely solely on patient self-reporting and computer-driven seizure detection are at risk of missing both generalized and complex partial seizures. Patients taking reduced doses of medications may suffer additional seizures in this setting. Also, some patients may have more than one seizure focus and a focus may be missed without 24-hr human observation. This is illustrated by a patient in our series with multiple foci. He was aware of most of his extratemporal seizures but was not aware of the seizures that arose from the contralateral temporal lobe, even though some of these included secondarily generalized tonic-clonic seizures. Fortunately, his events were detected by both human observation and computer seizure detection.

There are no studies of the effects of temporal lobectomy on seizure awareness. If lack of seizure awareness is mediated by postictal dysfunction of the temporal lobes, then anterior temporal lobectomy might be expected to alter the degree of awareness. After anterior temporal lobectomy, patients might be as likely, more likely, or less likely to recall seizures. None of the patients in this study had prior epilepsy surgery.

Drug studies are critically dependent on the patient's self-reporting of seizure frequency. Successful treatment of unrecognized complex partial seizures may convert the seizures to recognized simple partial events, and successful treatment of unrecognized secondarily generalized seizures may convert these seizures into complex partial events that are more likely to be recognized. Therefore, almost successful treatment of epilepsy may lead to a paradoxical increase in reported seizures. Studies of drug efficacy carried out in epilepsy monitoring units[9,10] with the patient under direct observation may be more reliable than outpatient-based studies. This study emphasizes the need for new methods of data gathering.

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Appendix. Seizure perception questionnaire

PATIENT QUESTIONS:

1) How many seizures do you have in a typical month?
   a) How many tonic-clonic? ____ per month
   b) How many complex partial? ____ per month
   c) How many simple partial? ____ per month

2) Do you always know when you have had a . . .
   a) Tonic-clonic seizure? yes no
   b) Complex partial seizure? yes no
   c) Aura? yes no

3) How often do your family members or friends tell you that you just had a seizure, even though you may not have been aware of one?
   a) How many tonic-clonic? ____ per month
   b) How many complex partial? ____ per month
   c) How many simple partial? ____ per month

4) Do you ever have brief episodes of confusion without knowing why? yes no

5) Do you ever get lost while walking around your neighborhood? yes no
   If yes, ____ per month

6) Have you ever suffered a serious injury (burn, cut, fracture, etc.) and not known how it happened?
   Yes No ____ per month

FAMILY MEMBER QUESTIONS:

1) How many seizures does the patient have in a month?
   a) How many tonic-clonic? ____ per month
   b) How many complex partial? ____ per month
   c) How many simple partial? ____ per month

2) Does the patient always know when he or she has had a . . .
   a) Tonic-clonic seizure? yes no
   b) Complex partial seizure? yes no
   c) Aura? yes no

3) Do you ever notice that he or she is confused and wonder whether a seizure just occurred?
   Yes No

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Accuracy of reported family histories of essential tremor

Article abstract—We studied the accuracy of reported family histories of essential tremor (ET) by questioning the patients in our clinic and subsequently by mail and phone. For individuals who continued to report a negative family history, we mailed a screening questionnaire to their first-degree relatives to further ascertain the presence of ET. On initial assessment, 67.7% of patients reported a positive family history of ET, but following all assessments, 96.0% of patients had a positive family history. We conclude that a negative family history of ET is often inaccurate, and that ET is primarily a hereditary disease.

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Essential tremor (ET) has long been recognized as an inherited disease.[1] Various studies report a positive family history, from 17 to 70%,[2-6] with autosomal dominant inheritance being the mode of transmission.[1,7] Because a negative family history may be unreliable, we studied the accuracy of reported negative family histories of ET.

Methods. All patients with ET at the Movement Disorder Clinic of the University of Kansas Medical Center had completed a data form which included the presence or absence of a family history of ET. A positive family history is defined as the reported presence of ET in at least one first-degree relative. We asked the patients on three separate occasions about their family history. After the clinic visit (first assessment), the patient was contacted by phone or mail to ascertain again the status of their family history of ET (second assessment). Several months later they were contacted by mail and asked whether each first-degree relative had ET and to provide their names and addresses (third assessment). They were free to contact their relatives. On receipt of a signed consent form and completed family information, first-degree relatives were contacted by mail. They were asked to sign a consent form and complete an 11-item screening questionnaire (table) designed to diagnose ET (fourth assessment).[8] Individuals were considered to be affected with ET if they answered positively to three or more of the 11 items.

Results. A total of 319 patients with ET were in the database as of August 1993. Of these, 216 (67.7%) reported a positive family history of tremor. When the 103 patients who reported a negative family history were contacted by phone or mail, four were found to have died, three did not want to participate, three could not be contacted, and five did not have a living or known first-degree relative. Seventeen more of the eligible remaining patients (233/304) now reported a positive family history—76.6% of the total group now having a positive family history. The 71 patients with a negative family history were contacted by mail and asked to provide the names and addresses of first-degree relatives and to identify those affected with tremor. Fifty-one patients did not respond, and another six patients reported a positive family history—94.5% (239/253). First-degree relatives of the remaining 14 individuals completed screening questionnaires by mail. From these screening questionnaires, four more probands were identified as having a positive family history, with at least one first-degree relative considered to have ET. Hence, a positive family history was found in 96% (243/253) of eligible and willing participants in our ET cohort.

Discussion. Investigators have tried to determine whether familial ET differs from "sporadic" ET clinically by body region affected, tremor frequency, age of onset, severity, gender distribution, response to alcohol, and response to pharmacologic treatment,[1,5] but no consistent differences have emerged. Nonfamilial, or "sporadic," ET is usually defined by a negative answer to an inquiry about family members with tremor. This negative answer could be incorrect for several reasons. The proband may not have frequent contact with relatives or have consciously observed them for tremor. Relatives may have died at a young age before expression of the gene. Furthermore, mild ET often goes undetected by family members. Even the social implications of a familial dis-

