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Conversations between community-based neurologists and patients with epilepsy: Results of an observational linguistic study

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ABSTRACT

An in-office linguistic study was conducted to assess neurologist–patient discussions of epilepsy. Naturally occurring interactions among 20 neurologists and 60 of their patients with epilepsy were recorded. Participants were interviewed separately postvisit. Transcripts were analyzed using sociolinguistic techniques. Of 59 patients taking antiepileptic drugs previsit, 44 (75%) discussed side effects with their neurologist. Side effect discussions were most often neurologist initiated. Postvisit, patients and neurologists often disagreed about which side effects were experienced. The presence of a caregiver (e.g., spouse) usually resulted in lengthier, more detailed discussions of side effects, without drastically increasing overall visit length. Discussions of mood- and behavior-related comorbidities occurred infrequently (14 of 60 visits); postvisit, neurologists stated that they felt that management of these conditions was outside their area of expertise. Communication gaps observed in discussions of epilepsy and its treatment warrant further exploration. Additional research is currently underway to assess the efficacy of a previsit assessment tool.

1. Introduction

The complex nature of epilepsy [1], the frequent co-occurrence of psychiatric symptoms and disorders among patients with epilepsy [2], and the potential negative side effects of antiepileptic drugs (AEDs) [3,4] pose significant challenges to patient care. Effective and efficient provider–patient communication is an important element of most chronic disease management; therefore, a careful and comprehensive assessment of communication between neurologists and patients with epilepsy can provide insight into how these important challenges are discussed. However, many studies of physician–patient communication about epilepsy rely on self-reported measures from instruments such as questionnaires and surveys [5,6]. To date, to the best of our knowledge, no research has analyzed in-office conversations between physicians and their patients with epilepsy. Also, to the best of our knowledge, no studies have compared actual visit dialogues with both parties' postvisit understanding of what occurred during the encounter.

An observational in-office study using accepted sociolinguistic methodologies [7–11] was conducted to capture naturally occurring conversations between neurologists, patients with epilepsy, and their caregivers (i.e., family members or close friends), if present. The study sought to identify gaps in communication and develop recommendations to improve in-office dialogue and to analyze how neurologists and patients discuss management of side effects and common comorbid conditions.

2. Methods

Prior to study initiation, a working group consisting of epilepsy experts (F.G., P.P., D.L., G.H., and J.C.) and linguistic specialists (C.E., M.O., and E.M.) convened to discuss study objectives, methodology, and analyses, with the goal of studying communication surrounding epilepsy in real-world office visits. The observational study

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received approval from the Independent Investigational Review Board, Inc. (IIRB) in October 2007, and fieldwork was conducted between November 2007 and January 2008. Letters of invitation were mailed to 1493 community-based neurologists chosen from a list of high-volume prescribers of AEDs. High-volume prescribers of AEDs were selected to maximize the likelihood of reaching community-based neurologists who treat a large number of patients with epilepsy (as opposed to those who focus on patients with other neurological conditions, e.g., Parkinson's disease, multiple sclerosis). A predetermined sample size of 20 neurologists had been chosen; the first 20 to reply to the invitation who met screening criteria (Table 1), were available during the relevant time frame, and agreed to participate were enrolled in the study (Table 2).

On previously agreed-on days, field researchers were sent to neurologists' offices. Office staff approached all patients who had regularly scheduled appointments and were likely to discuss epilepsy during that day's visit and invited them to take part in a study of physician–patient communication. Informed, written, HIPAA-compliant consent was obtained from all participants, after which the office visit was video- and audiotaped without the researcher or other observer present in the examination room. All research participants (i.e., neurologists and patients) were compensated for their participation based on fair market value for in-facility focus group research, but none was made aware of the study sponsor. Five patients were approached but refused to participate.

Immediately following the visit, the patient and caregiver(s) participated in video- and audiotaped interviews. At the end of the clinical day, neurologists were similarly interviewed regarding all their patients who had participated in the research that day. Medical records were brought into the interview to aid with recall. These postvisit interviews revealed the relative match or mismatch of participants' perceptions regarding issues discussed in the visit, including diagnoses, symptoms, medication regimen, side effects, and level of satisfaction with treatment. Given the asymmetric nature of the typical office visit (i.e., an interactional structure in which one party holds information that is sought by the other), the bulk of these interview questions were designed to uncover what providers meant to convey and what patients understood.

Prior to initiation of the study, a cohort of 60 patients (see Table 3) were chosen by the study sponsor and the authors as an appropriate sample for in-depth analysis, supported by previously published work in the area of physician–patient communication [12–14]. Because the taping took place without a guarantee that the topic would be discussed in enough detail for sociolinguistic analysis, patients were overrecruited; a total of 85 interactions were recorded. Twenty-three of these were excluded from the final study sample on review of the recordings: 8 did not have a confirmed diagnosis of epilepsy, 5 had mental challenges/cognitive impairment, 4 were too difficult to hear/understand (background noise, slurred speech, strong accents), 3 contained only an interaction between a nurse (not a physician) and patient, 2 did not have any conversation about epilepsy, and 1 physician violated the study protocol and pre-recruited the patient. Two more were excluded because the final sample size of 60 interactions had been reached.

All visits and postvisit interviews were transcribed using audio recordings, with videotapes providing a means for both quality control and nonverbal cues (e.g., nodding, shrugging shoulders).

Table 1
Physician screening criteria.

- Primary medical specialty: neurology
- Years in practice: >3 and <30
- >50 adult patients/week treated for all disorders and conditions
- >15 adult patients/week treated in-office for epilepsy

Table 2
Physician demographics, $n = 20$.

- In practice an average of 15 years
- Board-certified or board-eligible neurologists
- 95% were male
- Report spending an average of 97% of time in direct patient care
- Typically see 130 adult patients per week, 28 of whom have epilepsy

Table 3
Patient demographics, $n = 60$.

- Average age: 50 years
- 63% were female
- Average time since diagnosis: 13 years; 28% diagnosed $\leqslant$2 years
- 59 of 60 were on an antiepileptic medication before the visit
- 34% were seizure free for at least 1 year at the time of the visit
- 1 of 60 patients (2%) initiated a medication during the visit
- 4 of 60 patients (7%) changed medications during the visit
  - 2 switched medications
  - 1 added an additional medication
  - 1 stopped an existing medication

Body language and tone of voice, however, were not the focus of this research. Transcripts were analyzed using validated sociolinguistic models [7–11], including word- and turn-level analyses of conversation (e.g., analyses at the level of individual words and at each speaker's turn-at-talk). Specific linguistic analyses included, but were not limited to, quantification of topics discussed and time spent on each; quantification and description of questions asked and answered; word-level analyses of key vocabulary choices; and "open door/close door" of topics put forth or blocked in conversation (see Fig. 1 for overview of study methodology). Results of linguistic analyses were shared with the epilepsy experts of the working group, who provided feedback, allowing the findings to be framed in the specific context of epilepsy and its treatment.

3. Results

Encounters between neurologists and patients followed a relatively set algorithm. The mean visit length was 11.78 min (range: 2.13–39.92 min, SD = 6.50). Most conversations included a review of when the last office visit took place, a confirmation of current medications (including dosage and frequency), a brief discussion of recent seizure activity and/or medication side effects, a physical exam, and a review of test results, if applicable.

On average, 23% of the visit was spent discussing AEDs, most commonly a review of current regimen. Another 23% was spent on conversations of comorbid conditions. Postvisit, the most common patient self-reported conditions were arthritis, high cholesterol, hypertension/high blood pressure, and migraine headache. Discussions of seizures and related symptoms constituted 16% of visits on average; tests and test results made up 11%. Seven percent of the visit was spent discussing side effects, whereas conversations about mood-related issues constituted 4%. The full breakdown of topics discussed and average time spent on each is found in Fig. 2. The working group found the time spent talking about side effects and mood-related topics to be relatively brief, especially given the importance of these subjects in the clinical literature; therefore, it was decided that these would become the subject of further evaluation and analysis, and those results are summarized in this article.

Side effects were included in analysis if assessed by the physician, confirmed (or denied) by patients, and/or raised by patients of their own accord. Not included were side effects experienced in the past, potential side effects discussed as part of medication education for new prescriptions, and those ambiguously referred to during the physical examination.

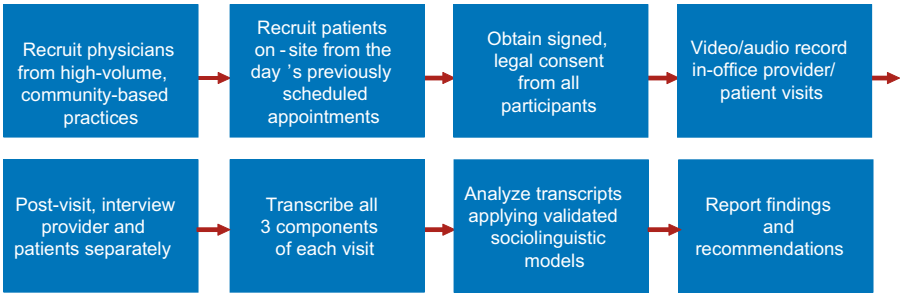

Fig. 1. In-office observational linguistic study design.

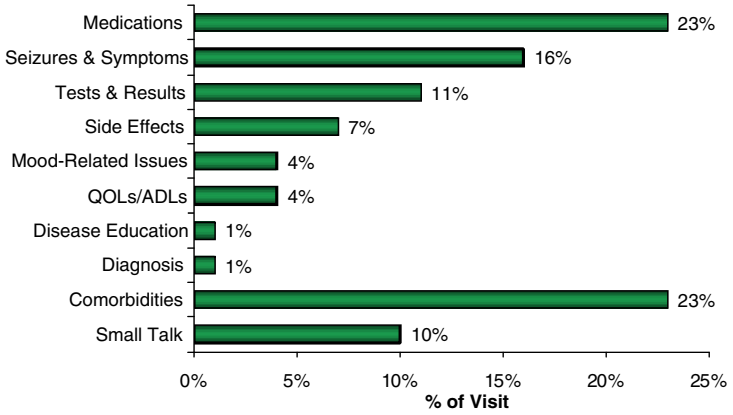

Fig. 2. Topics discussed and percent of visit spent on each.

Fifty-nine of 60 patients were being treated with an AED. Side effects were assessed by neurologists in 75% (44/59) of visits with these patients. In those visits, an average of four side effects per patient were assessed. Neurologists initiated 71% of all side effect assessments (134/190). Patients confirmed (i.e., stated that they experienced) 27% (36/134) of the side effects assessed. Patients raised 29% of all side effects assessed without being asked by a neurologist (56/190) (Table 4). The side effects that patients spontaneously brought up most often were:

- Vision problems, including double vision ($n = 9$ patients).
- Dizziness/lightheadedness ($n = 7$ patients).
- Cognition, that is, "drunk feeling," difficulty concentrating, memory problems, and "fuzzy" head ($n = 6$ patients).
- Drowsiness ($n = 6$ patients).

The number of side effect assessments (190) was calculated using the rationale described in the following example: If a visit contained one assessment each of three different side effects, it was counted as three assessments. If one side effect was assessed three separate times during a single visit, it was also counted as three assessments. Finally, if three different side effects were assessed in a single sentence, they were counted as three assessments.

Table 4
Side effects discussed in visits.

Side effect discussion	Number	%	
Physician initiated, patient confirms	36	19	
Physician initiated, patient denies	98	52	72%
Patient initiated	56	29	
Total	190	100	

Note. $N = 59$ visits with patients on AED therapy.

Visit companions such as spouses and parents were present in 19 of 60 visits (32%). These companions were involved in side effect assessments in 8 visits (13%). When a visit companion was present, the side effect information relayed was more detailed and greater in quantity (i.e., included discussions of three or more different side effects and/or was at least 60 s long) than in visits where patients were unaccompanied. The following is an example of the kind of detailed information provided by visit companions, when present:

Example: The presence of visit companions leads to more detailed side effect discussions (neurologist with 22-year-old female patient and her husband).

Husband:	This is—it's [AED].
Doctor:	[AED], right, for seizures.
Patient:	So I have to finish everything?
Husband:	Oh, that happens with seizures?
Doctor:	Yeah, because there were too many seizures, umm, with you and your age. Yeah.
Husband:	So she has to keep taking one at night and then one in the morning?
Doctor:	Yes.
Husband:	Those aren't the ones that give dizziness?
Doctor:	Sometime it does, but it's too low dose.
Husband:	And this, 500 mg?
Doctor:	Right.
Husband:	And then which one you think is the one giving her dizziness? This pill?
Doctor:	[AED]? That's for her migraine.
Husband:	Oh, that is for her migraine?
Doctor:	Yeah.
Husband:	So much more pills. Why you have so dizziness?
Doctor:	But I told you that—let this little resolve—it will go over time, she'll be fine.

Patient: So, just time.
Husband: Well, I—I—I—it's like I said to you too, [Name]. You have to give some time. You are really sick, very sick. I'll be with you at home, more in the hospital.

This type of assessment did not dramatically alter the overall visit length. Specifically, visits with lengthier, more detailed side effect assessments were 12.42 min long on average, compared with those without such assessments, which were 11.17 min long on average ($P = 0.5553$).

As illustrated here (Table 5), when asked postvisit, 33% (20/60) of neurologist–patient pairs did not agree on what side effects the patient actually was experiencing. In 16 patient postvisit interviews (27%), patients reported side effects that the neurologist was unaware of. These were most often sleep problems/drowsiness, headache, and vision problems. Half of the patients had not discussed these disputed side effects during their office visit.

Mood-related topics were discussed infrequently during neurologist–patient interactions or postvisit interviews with neurologists. Twenty-three percent of office visits contained conversations related to mood or behavioral symptoms, compared with 53% of postvisit interviews with neurologists and 65% of postvisit interviews with patients. Both neurologists and patients talked about mood-related subjects during their postvisit interviews with a field researcher that they did not address during their interaction with each other. Specifically, 65% (39/60) of patient postvisit interviews and 53% (32/60) of neurologist postvisit interviews with a field researcher included talk about mood-related subjects that was not addressed during office visits.

4. Discussion

Although extensive research has been conducted on the subject of the negative side effects of epilepsy medications [15], discussions of side effects were not observed in all visits with patients taking medication for epilepsy. Neurologists initiated the majority of all side effect discussions; however, in most instances, patients denied being affected by the side effects inquired about. This discrepancy was highlighted by the results of postvisit interviews with neurologists and patients. Administering a side effect screening tool or instrument prior to the office visit could result in a targeted, more successful conversation.

Visit companions facilitated discussion between neurologists and patients. When present, they provided additional information regarding side effects, leading to a lengthier and more detailed conversation. Companions were also able to provide information from a neutral perspective and could track changes in patients' behavior over time. By encouraging patients to bring a close friend or family member to regular office visits, neurologists could gain additional information to aid in treatment of epilepsy and management of side effects.

The neurologist/patient postvisit misalignment regarding which side effects affected patients is an important issue that warrants further exploration, especially because side effects of AEDs are closely related to quality of life [16,17]. One possible explanation for this disconnect is the lack of conversation occurring during visits about side effects. Specifically, in more than half of the cases where physicians and patients were misaligned, side effects were not discussed during the visit. When side effects were mentioned in visits, the majority of conversations focused on side effects that patients did not actually have; only 27% (36/134) of side effects were confirmed by patients as being issues that they actually suffered from. In addition, the complex nature of epilepsy and the variable nature of the side effects associated with its treatments may also lead to inadequate patient comprehension and subsequent confusion about the condition and potential treatment options.

Discussions of mood-related comorbidities occurred more often during postvisit interviews with neurologists and patients than in office visits. Some neurologists admitted feeling uncomfortable addressing these issues or believed that they fall outside their area of expertise, which they view as seizure control. Use of screening instruments for depression and other psychiatric comorbidities could facilitate neurologists' identification and treatment of these conditions [18].

This study has several limitations, and further research could refine the results described above. For example, practitioners in this sample were community-based general neurologists whose patients with epilepsy may or may not be representative of patients treated by primary care physicians or epileptologists. However, it is noteworthy that a majority (66%) of patients reported at least one seizure within the past year; they are therefore patients with uncontrolled epilepsy. Future research in a variety of clinical settings could examine if and how these different types of clinicians (e.g., primary care physicians, general neurologists, epileptologists) differ in their communication with patients with epilepsy. Additional research could also examine a larger patient sample and assess the roles of physician and patient age, gender, and socioeconomic status in conversations about epilepsy.

Postvisit interviews with patients and visit companions were conducted immediately after the physician–patient office interaction; however, interviews with neurologists were not conducted until the end of the clinical day. This may bias the comparison of postvisit outcomes. Although a study limitation, this was chosen after careful consideration as less harmful than other potential biases. For example, administering neurologist postvisit interviews immediately after the office visit would have been disruptive to the natural "flow" of the practice as it would have required an additional field researcher in the office and would have required the neurologist to pause between seeing patients. In addition, it would sensitize the neurologist to the interview questions, likely causing him or her to alter his or her behavior during subsequent patient interactions.

Participant awareness of being audio- and videorecorded is another potential study limitation; however, extensive research has been conducted on this subject, and several studies concluded that recording has little to no effect on study subject behavior [19–22]. In this instance, to minimize the "observer's paradox" [23], subjects were informed that the study was about physician–patient communication, but were *not* informed about the specific interest in side effects from epilepsy medication, mood-related comorbidities, their relationship to discussions of epilepsy and its treatment, or the study sponsor.

Table 5
Postvisit alignment regarding side effects. $n = 60$ physician postvisit interviews and 60 patient postvisit interviews.

Physician and patient aligned postvisit?	Number	%	
Yes—Physician and patient report exactly the same or no side effects	40	67	
No—Patient reports side effects, physician does not	11	18	
No—Physician reports side effects, patient does not	4	7	33%
No—Physician and patient report different side effects	5	8	
Total	60	100	

A continuation of this study is currently being conducted to measure the impact of a previsit assessment tool on neurologist–patient interactions. In addition to the actual in-office communication, outcomes such as visit length, neurologist and patient satisfaction with discussions, and any changes in treatment based on information learned during the interaction are also of interest.

5. Conclusions

Recent research has identified a number of areas that should be addressed when selecting AED therapy [24]. Addressing both side effects and comorbid conditions is important. Improved communication about important topics such as side effects and mood- or behavior-related comorbidities would provide neurologists with access to valuable information, optimizing care for patients with epilepsy.

Sociolinguistic analyses of in-office dialogues and postvisit interviews with neurologists and patients with epilepsy revealed that conversations about epilepsy, specifically regarding side effects and mood-related symptoms or psychiatric comorbidities, are areas for improvement. These dialogues require both increased quantity and improvement in content.

It is important to note that the presence of a lengthier and more detailed side effect discussion did not dramatically affect total visit length. Therefore, a communication intervention that results in a lengthier conversation about side effects in particular need not result in a longer visit overall. Such an intervention could also result in a more targeted discussion, an improvement over current, less than ideal, encounters. A recent study in migraine, for example, demonstrated that incorporating specific patient-centered interviewing techniques (e.g., asking an open-ended question) can elicit important diagnostic information without statistically increasing visit length [25,26].

Postvisit, neurologists were unaware of some side effects experienced by patients. By not asking about those side effects in the visit, neurologists missed an opportunity to learn information that could be helpful in the successful treatment of epilepsy. New communication strategies may help meet the specific needs of neurologists engaging in dialogue with patients who have epilepsy. Specifically, visit companions should be leveraged to act as advocates for patients as they appear to improve the side effect conversation. Furthermore, the use of in-office tools or questionnaires to assess side effects and/or mood may increase office efficiency and better enable neurologists to provide customized, patient-centered care [18,27–29]. Use of such strategies could result in more efficient and effective dialogues about the complex condition of epilepsy and its equally complex treatment.

Conflict of interest statement

Frank Gilliam is a consultant/speaker for Cyberonics, GlaxoSmithKline Ortho–McNeil, Pfizer Inc., and UCB.

Patricia Penovich is on the speakers bureaus of GlaxoSmithKline, Pfizer Inc., and UCB.

David M. Labiner has received research grants from Abbott Laboratories, Cyberonics, Eisai Inc., GlaxoSmithKline, Novartis, Ortho–McNeil, Pfizer Inc., UCB, and the Centers for Disease Control and Prevention. He is on the speakers bureaus of Abbott Laboratories, Cyberonics, Eisai Inc., GlaxoSmithKline, Novartis, Ortho–McNeil, Shire, and UCB. In addition, he is a consultant for Cyberonics, GlaxoSmithKline, Novartis, Ortho–McNeil, Pfizer, and UCB.

Gregory L. Holmes is on the speakers bureaus of GlaxoSmithKline and UCB and the Data Safety Monitoring Board of Eisai Inc. He is consultant to Pfizer Inc.

Joyce Cramer is a consultant to Lundbeck, Marinus Pharmaceuticals, Inc., Ortho–McNeil, Pfizer Inc., and UCB.

Corey Eagan, John M. Stern, Megan Onofrey, and Eileen Mathis have no financial interests to declare.

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