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Neurologist–patient communication about epilepsy in the United States, Spain, and Germany

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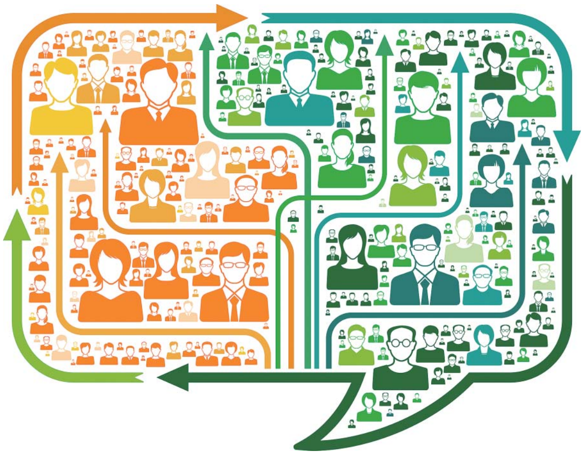
Abstract



Background

Effective communication between patients and their health care providers is recognized as critically important to improve the quality of health services for individuals with epilepsy. We aimed to describe in-office neurologist–patient conversations about epilepsy and focus on disease identification, shared decision-making, and care planning.

Methods

Transcripts and audio recordings of conversations between patients and neurologists in the United States, Spain, and Germany were analyzed linguistically in the topic areas of epilepsy identification and diagnosis, disease education, treatments, and care planning. Analyses included word-level assessments, topic switching, strategies of information elicitation, identification of topics discussed, quantification of questions asked, and assessment of types of questions asked.

Results

Conversations of 17 neurologists in the United States, 12 in Spain, and 6 in Germany, with 50, 20, and 16 patients, respectively, were analyzed. Neurologists tended to utilize an event-based, patient-friendly vocabulary to refer to seizures, and in the United States, they avoided using the term "epilepsy." Regardless of who initiated the treatment discussion, the neurologists in all 3 countries were unilaterally responsible for the treatment decision and choice of medication. When describing a new medication, neurologists most often discussed potential side effects but did not review potential benefits. Neurologists rarely defined seizure control and did not ask patients what seizure control meant to them.

Conclusions

We identified opportunities related to vocabulary, decision-making, and treatment goal setting that could be targeted to improve neurologist–patient communication about epilepsy, and ultimately, the overall treatment experience and outcomes for patients.

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Epilepsy is a common neurologic disorder associated with economic, social, and emotional costs for individuals and their families.[1] The need for patient-centered care, with a focus on the patient, family, and effective communication, has been emphasized in epilepsy care. Improving communication between patients and their health care providers is fundamental to enhancing the quality of health services for individuals with epilepsy.[1,2] Communication skills are as important as diagnostic skills.[3] Taking into consideration how patients communicate about their seizures can help neurologists differentiate between epilepsy and nonepileptic seizures,[4] as well as identify and rank treatment goals.

Limitations in the communication about epilepsy between neurologists and patients in the United States have been identified.[5,6] There is no agreement between patients' perceptions and neurologist-documented counseling, especially regarding epilepsy syndrome, etiology, or seizure type, and reproductive counseling.[5] Similarly, an in-office linguistic study showed that even though patients and neurologists spend 23% of their time during the office visit discussing the side effects of antiepileptic drugs, 33% of neurologist–patient pairs disagreed postvisit on the side effects that the patient was experiencing.[6] The aim of the current study was twofold: to broadly describe and compare in-office conversations about epilepsy between neurologists and patients in the United States, Spain, and Germany, and to focus on aspects of neurologist–patient communication that had not been studied previously, especially disease identification, shared decision-making, and care planning.

Methods

Participant recruitment

Letters of invitation were mailed or faxed to 20 board-certified neurologists in the United States, 12 in Spain, and 6 in Germany, who had previously agreed to participate in the Verilogue research program. Typically, physicians participating in the Verilogue research program are generalists who treat patients with many different conditions within their specialty. All neurologists agreed to participate in the current research. The neurologists 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 or data analysis plan. Patients who had regularly scheduled visits during which they were likely to discuss epilepsy were invited to participate in the study by the office staff. Patients were informed that the aim of the study was to improve communication between health care providers and patients.

Standard protocol approvals, registrations, and patient consents

Informed and written consent was obtained from all patients and neurologists. The consent obtained from the US participants complied with the Health Insurance Portability and Accountability Act of 1996.

Data collection

Neurologists recorded their conversations with patients using a proprietary smartphone application or a digital recording device between February 2014 and January 2016. One conversation was recorded for each participating patient. Recordings of 2 to 3 conversations per neurologist per month were uploaded to a secure database along with limited patient chart information. Based on more than 10 years of experience in dialogue research,[7,8] we determined that a sample size of 50 conversations in the United States, 20 in Spain, and 16 in Germany was sufficient for an in-depth, accurate analysis.

Analysis

Neurologist–patient conversations were de-identified and transcribed into the language in which they were recorded. The most relevant and representative conversations recorded with patients ≥16 years old were selected for the analysis. Relevant conversations were defined as those in which at least 1 of the following 4 conversation topics of interest was discussed: identification and diagnosis of epilepsy, disease education, treatments (i.e., selection, titration, addition, and change of medication), and care planning. Very short conversations (≤4 minutes) were less likely to be selected because brief, check-in visits usually provide little information to analyze. Similarly, conversations with patients with well-controlled seizures during which little discussion of seizures, side effects, or possible treatment change took place were also less likely to be selected.

Transcripts and audio recordings of conversations were analyzed in the language of the recording based on validated sociolinguistic practices of discourse analysis and conversation analysis as characterized by Gumperz.[9,10] Briefly, the transcripts and audio recordings were reviewed qualitatively line by line, and the results of various analyses (e.g., frame analysis, discourse markers, stance, mental models, genre, and intertextuality) were cataloged. These linguistic analyses were applied in the topic areas of identification and diagnosis of epilepsy, disease education, treatments, and care planning. Analyses included word-level assessments, topic switching, strategies of information elicitation (including closed- and open-ended lines of questioning), identification of topics discussed, quantification of questions asked, and assessment of types of questions asked. Trained linguists who were native speakers of the language of the recorded conversation and who were residents of the country in which the conversation was recorded conducted these analyses to ensure that cultural and linguistic nuances were identified and understood. Transcripts of conversations recorded in Spanish and German were also translated into English. Quantitative comparison of results from the 3 countries was not performed.

Results

Participant characteristics

Twenty neurologists in the United States, 12 in Spain, and 6 in Germany submitted recordings of 245, 125, and 62 conversations with their patients, respectively. Conversations submitted by 3 neurologists in the United States were excluded because they did not meet the relevance criteria. A total of 50 conversations in the United States, 20 in Spain, and 16 in Germany were included in the analysis. The majority of neurologists (88%) included in the United States were based in a private practice, whereas in Spain the majority of neurologists (83%) were based in a community hospital or clinic, and in Germany 50% of neurologists were based in a private practice and 50% in a hospital (table 1). Most neurologists were general neurologists, except for 2 epileptologists in the United States and 7 movement disorder specialists in Spain. In the United States, 13 conversations with newly or recently diagnosed patients were recorded, as well as 9 conversations in Spain and 9 in Germany (table 2). Eight patients in the United States, 2 in Spain, and 6 in Germany initiated antiepileptic therapy for the first time.

Neurologist–patient dialogue

The median duration of visits in the United States was 6 minutes 40 seconds (range, 2 minutes 12 seconds to 42 minutes 37 seconds), 8 minutes 37 seconds in Spain (range, 2 minutes 13 seconds to 19 minutes 53 seconds), and 13 minutes 24 seconds in Germany (range, 7 minutes 28 seconds to 32 minutes 16 seconds). For the conversations excluded from the analysis, the median duration of visits was 7 minutes 51 seconds in the United States (range, 1 minute 32 seconds to 72 minutes 34 seconds; n = 195), 7 minutes 29 seconds in Spain (range, 2 minutes 8 seconds to 24 minutes 13 seconds; n = 105), and 11 minutes 40 seconds in Germany (range, 6 minutes 49 seconds to 42 minutes 30 seconds; n = 46). The conversational flow during the analyzed visits did not vary greatly from country to country, although neurologists in Spain spent less time discussing patients' current treatment and neurologists in Germany spent more time discussing possible pregnancy as it relates to potential future treatments with female patients (figure).

> Neurologists often had to probe deeply to uncover symptoms of focal-onset seizures and convince patients that these are in fact seizures and require treatment.

Comparison of neurologist–patient communication in the United States, Spain, and Germany

Symptom discussion

In all 3 countries, neurologists used open- and closed-ended questions to discuss patients' seizures. Neurologists and patients referenced caregivers' accounts to understand seizures, and they used event-based language to describe seizures. Neurologists utilized patient-friendly vocabulary to refer to generalized and focal seizures, for example, the terms

Table 1 Neurologist characteristics

	Neurologists			
Characteristics	United States (n = 17)[a]	Spain (n = 12)	Germany (n = 6)	All (n = 35)
Male, n (%)	14 (82)	5 (42)	6 (100)	25 (71)
Years in practice, n (%)				
0–4	2 (12)	0 (0)	0 (0)	2 (6)
5–9	0 (0)	2 (17)	0 (0)	2 (6)
10–14	1 (6)	2 (17)	2 (33)	5 (14)
15–20	5 (29)	3 (25)	0 (0)	8 (23)
21–25	5 (29)	4 (33)	4 (67)	13 (37)
26–30	4 (24)	1 (8)	0 (0)	5 (14)
Primary practice setting, n (%)				
Community hospital/clinic	2 (12)	10 (83)	1 (17)	13 (37)
Group private practice, office-based	10 (59)[b]	1 (8)	2 (33)	13 (37)[b]
Individual private practice, office-based	5 (29)	0 (0)	1 (17)	6 (17)
Teaching/academic hospital	1 (6)[b]	1 (8)	2 (33)	4 (11)[b]

[a] Twenty neurologists recorded conversations with their patients with epilepsy. Conversations submitted by 3 neurologists did not meet the relevance cutoff and were not included in the analysis.
[b] One US neurologist reported 2 primary practice settings: group private practice and teaching/academic hospital.

Table 2 Patient characteristics

Characteristics	Patients United States (n = 50)	Spain (n = 20)	Germany (n = 16)	All (n = 86)
Male, n (%)	23 (46)	12 (60)	8 (50)	53 (61)
Average age (range), y	41 (18–79)	41 (16–72)	43 (19–77)	41 (16–79)
Time since diagnosis, y, n (%)				
0–1[a]	16 (32)	10 (50)	10 (63)	36 (42)
1–5	23 (46)	3 (15)	2 (12)	28 (32)
>5	10 (20)	7 (35)	4 (25)	21 (25)
Unknown	1 (2)	0 (0)	0 (0)	1 (1)
Visits to the neurologist within the last year, n (%)				
0	20 (40)	4 (20)	5 (31)	29 (34)
1–4	23 (46)	14 (70)	10 (63)	47 (55)
5–12	7 (14)	2 (10)	1 (6)	10 (11)
Treatment, n (%)				
Monotherapy	26 (52)	10 (50)	10 (62)	46 (53)
Adjunctive therapy	24 (48)	10 (50)	5 (31)	39 (45)
Unknown	0 (0)	0 (0)	1 (6)	1 (1)

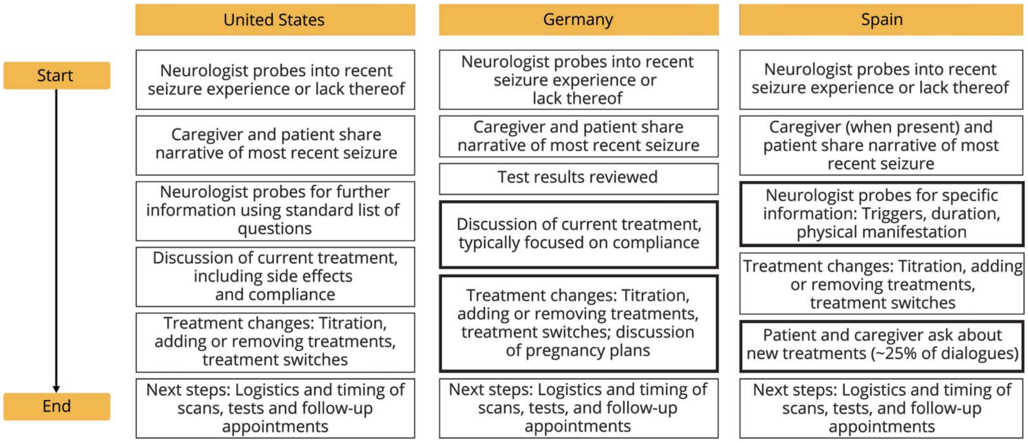
[a] This includes conversations during which the patient was diagnosed with epilepsy.

"attacks," "episodes," or "events" (used in addition to the term seizures; table 3, insight A). Patients did not always recognize that they had a focal seizure and described having focal seizures as being "out of it," "disoriented," or "not all there." Neurologists often had to probe deeply to uncover symptoms of focal seizures and convince patients that these are in fact seizures and require treatment.

Use of the term epilepsy

In the United States, 7 neurologists used the term "epilepsy," but often not in the context of diagnosis, and one of the neurologists stated, "we don't treat seizures, we treat epilepsy." Instead, almost all neurologists focused on individual seizure events and understanding the details of each event, and referred to the condition as seizures, not epilepsy, regardless of seizure

Figure Neurologist–patient conversation flow



Conversation elements that differentiate conversations in Spain and Germany from conversations in the United States are outlined in bold.

Table 3 Key communication insights and select quotes from patients (P), caregivers (C), and neurologists (N)

Insight	United States	Germany	Spain
(A) Patients and neurologists used patient-friendly vocabulary to describe focal seizures	N: "And during that time you would stay awake, but you were not there" C: "Eyes roll backwards and blank smile"	N: "Tell me exactly again, how that, hmm, how it went from your point of view" P: "Yes, I sat at the computer at work and then, my right hand, is, uh, became a little bit numb"	N: "Do you become paralyzed?" P: "Well, I don't know exactly" N: "Looking blank, what have they told you? Because it surely" P: "They've told me that I fall down, I fall . . . I'm standing and suddenly I fall"
(B) In the United States, neurologists avoided using the term "epilepsy"; in Spain and Germany, they used the term "epilepsy" and referred to it as a chronic condition	N: "You reported having been diagnosed with seizures. . . [I] want to put you back on the seizure medicine. . . because you were having the spells recently pretty often"	N: "There is a genetically determined epilepsy"	N: "Epilepsy is like almost all the diseases. There are many types. . . . They are chronic diseases that you try to reduce it with the medication or, if you can, remove the crisis"
(C) Neurologists focused on side effects when describing a new medication	N: "The reasons I would have to switch are that your medication X long term can have more side effects than some of the newer medicines can . . . the other thing is the newer ones you don't really need bloodwork with them. [They are] cleaner medications"	N: "You will have to slowly increase the dose, or else it might give you eczema"	N: "We don't want to stop the seizure completely, if that's going to alter your normal daily life [because of side effects], okay?"
(D) Neurologists recommended one specific medication to the patient	N: "There [are] about a dozen different medications. The one I want to start you on is called X"	N: "We would like to begin straight away and give a drug called X. You've probably never heard of it. It is an antiepileptic. X is the substance that you take as a tablet just once a day"	N: "[Current medication X] is not enough but it's the best drug and this one is doing you good. So, better than switching it, X is a good drug"
(E) Patients and neurologists preferred to maintain the existing treatment and control level	N: "When somebody's doing so well, last thing I would do is change, you know . . . the dose or the medications or, so just leave you alone"	N: "Regarding the epilepsy. . . I wouldn't change anything on this concept" P: "To leave it the same?" N: "Yes, I mean, why should we do it?"	P: "I am taking it because I don't want this to happen again"
(F) Patients hesitated to start or change medication	P: "What I'm afraid of with that is that then I would have to, uh, get used to it on the stomach side effects. . . . I'm worried that because, for the most part, everything like seizure wise, you know, is doing great"	P: "I don't want that right now, well I have a lot of work to do and I have to finish a lot of things in the next months. . . Maybe the medication will make me more prone to epileptic seizures . . . Will the medication make me weaker? I mean, what are the side effects?"	N: "Some sort of treatment should be started. . ." P: "And is it worth it or not?"
(G) Neurologists in all 3 countries asked about seizure frequency, but control was vaguely defined	N: "If you feel that, uh, you want to take control, more control of seizure, then we can add something"	N: "Are the seizures almost gone now, or?" P: "Yes, from time to time, well, uh, they are not completely gone, but I feel I am more stable now"	P: "Sometimes, there was a time that I had up to 3 [seizures in one day]" N: "Three times. Well, very well. We're going to continue with this treatment, which has been the best you've experienced, okay?"
(H) Neurologists in the United States did not set treatment goals; in Germany and Spain, they sometimes described seizure freedom as the treatment goal	N: "Let's see if we can get some higher results with a higher dose"	N: "And that's actually what, what the goal of the treatment is, that you with, with a good tolerance that you will be free of seizures, right"	N: "I hope with this adjustment of the medication that we did now, when you come to the revision, you come like new."

In Germany, neurologists discussed seizure triggers extensively with patients, whereas triggers were not emphasized to this extent in Spain and the United States.

frequency (table 3, insight B). However, use of the word "epilepsy" (or not) had no effect on whether a patient in the United States would accept the treatment recommendation. Treatment-experienced patients did not hesitate to accept treatment whether epilepsy was mentioned or not. Only 2 of the newly diagnosed patients were told that they have epilepsy. On the other hand, neurologists in Spain and Germany frequently used the term "epilepsy" to describe the patient's condition and "epileptic seizures" to describe individual seizure events. In contrast to neurologists in the United States, neurologists in Spain and Germany emphasized epilepsy as a chronic condition instead of a series of events, and they used examples of other chronic diseases when talking to newly diagnosed patients.

Disease education

In Germany, neurologists discussed seizure triggers extensively with patients, whereas triggers were not emphasized to this extent in Spain and the United States. Neurologists in Germany educated patients about potential triggers and sometimes used the inability to completely avoid triggers as a rationale to start treatment. They used patient-friendly metaphors (e.g., the brain is like a computer) to educate newly diagnosed patients about seizure triggers and epilepsy.

Decision-making

Even though focal seizures often did not trigger an urgent reaction from patients, neurologists saw the seizures as a reason to change or start treatment. The neurologists in all 3 countries were unilaterally responsible for the treatment decision and choice of medication. When describing a new medication, neurologists most often discussed potential side effects and did not review potential benefits (table 3, insight C). They did not elicit the patients' thoughts on the medication selection after reviewing the medication's details. They recommended one specific medication to the patients and only occasionally noted that other options exist, but they never offered multiple options to the patients (table 3, insight D).

None of the patients in this study asked about other options when the neurologist recommended a medication. Patient and caregiver involvement in the treatment discussion was limited to describing side effects or asking about the potential side effects of new medication. Newly diagnosed patients were reluctant to begin medication. Patients who believed that their disease was relatively controlled preferred to maintain their existing seizure control and medication (table 3, insight E). They hesitated to change medications (table 3, insight F), even if a new medication may offer them better seizure control, because they perceived the potential risks of the new medication, and transition to it, to outweigh the potential benefits. Even though caregivers bore the primary burden of explaining the patient's condition, they infrequently advocated for a treatment change for the patient.

Defining seizure control

Although nearly all treatment changes were driven by seizure control or lack thereof, neurologists rarely actually defined seizure control and did not elicit from the patients what seizure control meant to them (according to some patients, having 4 seizures in 1 year was equivalent to good control, whereas for others, 1 seizure per week was satisfactory). In all 3 countries, neurologists sometimes asked about seizure frequency, but they did not describe a threshold to differentiate between good and poor seizure control (table 3, insight G).

Setting treatment goals

When prescribing medications, the US neurologists often did not set treatment goals, whereas neurologists in Spain and Germany sometimes referred to seizure freedom as the treatment goal (table 3, insight H).

Discussion

The results of this analysis provide insight into the nature of communication about epilepsy between neurologists and patients and their caregivers in the United States, Spain, and Germany. Neurologists from all 3 countries tended to avoid medical terminology and instead to use patient-friendly language when discussing seizures with patients. In all 3 countries, patients were often unaware that some types of focal seizures might be subtle and without obvious loss of consciousness; therefore, the patient-friendly language used by the neurologists to refer to seizures may have helped the patients and caregivers provide detailed descriptions of their experiences. This avoidance of medical terminology and the use of euphemisms may improve patients' understanding of their condition, given that patients may not comprehend many of the medical terms commonly used by health care providers.[11–13]

In this study, the US neurologists, in contrast to neurologists in Spain and Germany, avoided using the term "epilepsy" and did not convey that seizures are a sign of a chronic condition that requires ongoing management, which may leave patients with a gap in their knowledge and understanding of the disease. This avoidance of clearly providing a diagnosis of epilepsy may affect patient care through misdirection of patients who seek information about their diagnosis after the neurologist consultation. Not knowing their underlying diagnosis, patients would be hampered in identifying what ancillary information is relevant to them.

When discussing treatment options in the current study, neurologists tended to focus on medication side effects rather than on benefits. However, according to the clinical guideline of the American Academy of Neurology (AAN) and American Epilepsy Society, neurologists should inform patients reporting their first unprovoked seizure that the side effects associated with epilepsy treatment are usually mild and reversible and that the risk of side effects ranges from 7% to 31%.[14] Side effects of antiepileptic treatment can negatively affect patient quality of life and are an important consideration when making a treatment decision.[15] In the current study, established patients hesitated to switch medications for fear of new side effects that could be associated with the new medication. Therefore, discussing the benefits, in addition to the side effects associated with available medication options, could help patients make an informed decision.[16]

In the neurologist–patient conversations examined in this study, neurologists did not share multiple treatment options and largely made the treatment decisions in all 3 countries without patient input; that is, they did not engage in shared decision-making with their patients. Shared decision-making is an approach in which health care providers and patients make decisions collaboratively through utilization of the best available evidence.[17,18] It involves checking for patients' goals and preferences for managing their condition.[19] Health care providers encourage patients to consider management options, including the benefits and risks of each option.[17,19] Patients assist in selecting the course of action that suits their preferences and their conclusions regarding options. Some patients may prefer to delegate the decision-making to their health care providers, but a systematic review of patient preference for decision-making showed that, in 63% of studies, most patients preferred to take an active part in making decisions.[20] However, this proportion may vary, depending on the health of the population, decision to be made, context, and relationship with the health care provider.[20,21] In the chronic neurologic disease population, most patients with Parkinson disease want to be involved in information exchange and deliberation but may prefer to delegate decisions made during late-stage disease to the health care provider.[21] The current study, which shows limited shared decision-making in neurologist–patient communication, may establish the baseline for future studies elucidating the effect of shared decision-making on patient outcomes in epilepsy.

Shared goal setting is part of the process of decision-making, with the ultimate aim of defining patient preferences.[22] The neurologists in this study often did not discuss treatment goals with their patients and did not always elicit what seizure control meant to patients. Setting treatment goals enables health care providers to focus on the underlying problem and may narrow the number of available treatment options, making the final treatment decision easier.[23] In addition, setting treatment goals improves the ability of health care providers to monitor treatment.[24] Discussing how the treatment would work toward the defined level of control could also proactively uncover and address potential barriers to adherence.[25] A patient who actively participates in the discussion about treatment goals becomes an informed partner with improved adherence.[23] Shared goal setting can lead to a sense of ownership and accountability and has been found to increase self-management skills in patients with diabetes.[26] Differences in the definition of seizure control and lack of agreement on the level of control can diminish patients' ability to evaluate the efficacy of their medication and, subsequently, the need for medication changes.

The study has several limitations. First, conversations analyzed in the study were selected for their relevance to the study objectives, which may have biased the results and led to underestimation or overestimation of communication gaps. In addition, differences in communication patterns observed in the current study may have been influenced by differences in health care systems, sociodemographic makeup, and cultural characteristics of the 3 countries. Because the study populations in all 3 countries were small, the results may not be representative of the cultural differences between the countries. Similarly, demographic characteristics of the neurologists participating in the study may not have been representative of all neurologists.[27] Furthermore, the presence of a recording device may have affected the behavior of the neurologists, patients, and caregivers. Because the participants were not videotaped, nonverbal communication was not captured. Also, the historical context of the conversation was not documented; therefore, not all aspects of the neurologist–patient interaction may have been considered. Finally, data from this study were collected through a series of naturally occurring, in-office conversations with broad, qualitative results. Validated quantitative measures of neurologist and patient perceptions were not used in this study.

In this multinational study, we identified opportunities concerning vocabulary, decision-making, and treatment goal setting that could be targeted to improve neurologist–patient communication (table 3). The neurologist–patient conversations about epilepsy could be optimized by using the following evidence-based strategies: (1) tailoring information to patients' needs[28]; (2) striking a balance between using vocabulary and language that is understandable to patients but that also conveys an appropriate level of disease awareness and education (based on table 3, insights A and B), which may empower patients to take a more active role in decision-making; (3) discussing potential benefits and risks (including side effects and uncertainties) of medications in a balanced way (addressing table 3, insight C)[19,28]; (4) creating an awareness of treatment options (addressing table 3, insight C)[28]; (5) engaging patients in a conversation to uncover their preferences, challenges, and treatment goals, and using this information to formulate preferred treatment recommendations (based on table 3, insights E and F)[19,28]; (6) agreeing to a treatment decision that includes patient's views and preferences (based on table 3, insights E and F)[19,28]; and (7) setting shared treatment goals[22] and defining control (addressing table 3, insights G and H).

These recommendations could contribute to improving the quality of epilepsy care as outlined by the AAN, particularly the requirement for education about all facets of epilepsy and the recommendation for neurologists to engage patients and caregivers in decision-making.[29] Future work should be focused on developing and testing interventions for neurologists and patients or their caregivers to help improve conversations about epilepsy to optimize the overall treatment experience for patients.

Author contributions

J.M. Stern: data review and critical revision of manuscript for intellectual content. F. Cendes: data review and critical revision of manuscript for intellectual content. F. Gilliam: data review and critical revision of manuscript for intellectual content. P. Kwan: data review and critical revision of manuscript for intellectual content. P. Ryvlin: data review and critical revision of manuscript for intellectual content. J. Sirven: data review and critical revision of manuscript for intellectual content. B. Smith: data review and critical revision of manuscript for intellectual content. A. Adomas: manuscript preparation. L. Walter: study design, data analysis, and critical revision of manuscript for intellectual content.

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Disclosure

J.M. Stern serves on scientific advisory boards for UCB and Lundbeck; serves as Associate Editor for *MedLink Neurology* and on the editorial board of *International Journal of Epilepsy*; receives publishing royalties for *Atlas of EEG Patterns, 2nd ed.* (Lippincott Williams & Wilkins, 2013) and *Atlas of Video-EEG Monitoring* (McGraw-Hill, 2011); serves on speakers' bureaus for UCB, Sunovion, Eisai, Cyberonics, and Lundbeck; practices clinical neurology (epilepsy) at UCLA (50% of effort); and receives research support from Leff Family Foundation. F. Cendes has served as a consultant for and received funding for travel and speaker honoraria from UCB; serves as an Associate Editor for *Epilepsia* and on the editorial boards of *Neurology®*, *Epilepsy Research*, *Arquivos de Neuro-psiquiatria*, and *Epilepsy and Behavior*; receives research support from Fundação de Amparo à Pesquisa do Estado de São Paulo (FAPESP) and Conselho Nacional de Pesquisa (CNPq) Brazil; and is a member of the Diagnostic Methods Commission for International League Against Epilepsy. F. Gilliam serves on the editorial board of *Epilepsy Currents*. P. Kwan serves on scientific advisory boards for Eisai and UCB Pharma; has received funding for travel and/or speaker honoraria from UCB and Novartis; served as an Associate Editor of *Epilepsy Research*; is author on patents re: Detection of HLA genotype and Microfluidic platform and Method for Controlling the Same; receives publishing royalties for *Fast Facts: Epilepsy (revised 4th ed.)* (Health Press, 2011); and receives research support and/or honoraria from Eisai, GlaxoSmithKline, Johnson & Johnson, Pfizer, UCB Pharma, Australia Research Council (DP140101967), Health and Medical Research Fund (01120086, 01120186), National Health & Medical Research Council (APP1103979), and RMH Neuroscience Foundation. P. Ryvlin serves on a scientific advisory board for UCB and as Associate Editor of *Epilepsia*. J. Sirven has been a consultant for Acorda Therapeutics, UCB, Inc., and NeuroPace; serves on scientific advisory boards for Eisai, Upsher-Smith, and Epilepsy Foundation; has received funding for travel from Epilepsy Foundation; serves on the editorial board of *Epilepsy.com*; receives publishing royalties from *Up to Date* and for *Clinical Neurology of the Older Adult* (Lippincott Williams & Wilkins, 2008); has completed projects for Medscape; receives research support from NIH/NINDS and Epilepsy Foundation; and is on the Board of Directors of the American Brain Foundation. B. Smith is employed by Spectrum Health Medical Group, which received compensation from UCB, Inc., for Dr. Smith's contributions; and has served on a scientific advisory board and as a consultant for UCB. A. Adomas is an employee of MicroMass Communications, Inc, which has received funding from UCB, Inc. L. Walter was Senior Analyst for Verilogue, Inc. (2014–2017), which has received funding from UCB, Inc., and is currently Research Manager for W2O Group (October 2017-present). Full disclosure form information provided by the authors is available with the full text of this article at Neurology.org/cp.

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References

1. Institute of Medicine Committee on the Public Health Dimensions of the Epilepsies. Epilepsy Across the Spectrum: Promoting Health and Understanding. Washington, DC: National Academies Press; 2012.
2. Bennett L, Bergin M, Gooney M, Doherty CP, Synnott C, Wells JSG. Epilepsy services in Ireland: 'A survey of people with epilepsy in relation to satisfaction, preferences and information provision'. Epilepsy Res 2015;113:11–18.
3. Haslam D. Communication skills are as important as diagnostic skills. Practitioner 2016;260:35.
4. Plug L, Sharrack B, Reuber M. Conversation analysis can help to distinguish between epilepsy and non-epileptic seizure disorders: a case comparison. Seizure 2009;18:43–50.
5. Moura LMVR, Carneiro TS, Thorn EL, et al. Patient perceptions of physician-documented quality care in epilepsy. Epilepsy Behav 2016;62:90–96.
6. Gilliam F, Penovich PE, Eagan CA, et al. Conversations between community-based neurologists and patients with epilepsy: results of an observational linguistic study. Epilepsy Behav 2009;16:315–320.
7. Goff SL, Mazor KM, Ting HH, Kleppel R, Rothberg MB. How cardiologists present the benefits of percutaneous coronary interventions to patients with stable angina: a qualitative analysis. JAMA Intern Med 2014;174:1614–1621.
8. Ubel PA, Zhang CJ, Hesson A, et al. Study of physician and patient communication identifies missed opportunities to help reduce patients' out-of-pocket spending. Health Aff 2016;35:654–661.
9. Gumperz JJ. Discourse Strategies. Cambridge: Cambridge University Press; 1982.
10. Gumperz JJ. On interactional sociolinguistic method. In: Sarangi S, Roberts C, eds. Talk, Work and Institutional Order: Discourse in Medical, Mediation and Management Settings. Berlin: Mouton de Gruyter; 1999:453–471.
11. Lerner EB, Jehle DVK, Janicke DM, Moscati RM. Medical communication: do our patients understand? Am J Emerg Med 2000;18:764–766.
12. Graham S, Brookey J. Do patients understand? Perm J 2008;12:67–69.
13. Hadlow J, Pitts M. The understanding of common health terms by doctors, nurses and patients. Soc Sci Med 1991;32:193–196.

14. Management of an unprovoked first seizure in adults: summary of evidence-based guideline for clinicians. American Academy of Neurology and American Epilepsy Society. https://www.aan.com/Guidelines/home/GetGuidelineContent/688. Published 2015. Accessed March 5, 2018.
15. Witt J-A, Elger CE, Helmstaedter C. Which drug-induced side effects would be tolerated in the prospect of seizure control? Epilepsy Behav 2013;29:141–143.
16. Madsen C, Fraser A. Supporting patients in shared decision making in clinical practice. Nurs Stand 2015;29:50–57.
17. Elwyn G, Laitner S, Coulter A, Walker E, Watson P, Thomson R. Implementing shared decision making in the NHS. BMJ 2010;341:c5146.
18. Stiggelbout AM, Van der Weijden T, De Wit MPT, et al. Shared decision making: really putting patients at the centre of healthcare. BMJ 2012;344:e256.
19. Brand PLP, Stiggelbout AM. Effective follow-up consultations: the importance of patient-centered communication and shared decision making. Paediatr Respir Rev 2013;14:224–228.
20. Chewning B, Bylund C, Shah B, Arora NK, Gueguen JA, Makoul G. Patient preferences for shared decisions: a systematic review. Patient Educ Couns 2012;86:9–18.
21. Zizzo N, Bell E, Lafontaine AL, Racine E. Examining chronic care patient preferences for involvement in health-care decision making: the case of Parkinson's disease patients in a patient-centered clinic. Health Expect 2017;20:655–664.
22. Bigi S. Key components of effective collaborative goal setting in the chronic care encounter. Commun Med 2014;11:103.
23. De Vries TPGM, Henning RH, Hogerzeil HV, Fresle DA. Guide to Good Prescribing. Geneva: World Health Organization; 1994.
24. Tichelaar J, Uil den SH, van Antonini NF, Agtmael MA, de Vries TPGM, Richir MC. A 'SMART' way to determine treatment goals in pharmacotherapy education. Br J Clin Pharmacol 2016;82:280–284.
25. Atreja A, Bellam N, Levy SR. Strategies to enhance patient adherence: making it simple. MedGenMed 2005;7:4.
26. Langford AT, Sawyer DR, Gioimo S, Brownson CA, O'Toole ML. Patient-centered goal setting as a tool to improve diabetes self-management. Diabetes Educ 2007;33:139S–144S.
27. Adornato BT, Drogan O, Thoresen P, et al. The practice of neurology, 2000–2010: report of the AAN Member Research Subcommittee. Neurology 2011;77:1921–1928.
28. Epstein RM, Alper BS, Quill TE. Communicating evidence for participatory decision making. JAMA 2004;291:2359–2366.
29. Fountain NB, Van Ness PC, Bennett A, et al. Quality improvement in neurology: epilepsy update quality measurement set. Neurology 2015;84:1483–1487.