



Patient emotions and perceptions of antiepileptic drug changes and titration during treatment for epilepsy



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ABSTRACT

Objective: To investigate the impact of antiepileptic drug (AED) change and dose titration on the emotional well-being of patients with epilepsy.

Methods: Members of an online epilepsy community were invited to voluntarily participate in an online survey. The cross-sectional anonymous survey consisted of 31 multiple choice questions balanced in terms of variety and positivity/negativity of emotions concerning participants' most recent AED change. To substantiate survey results, spontaneous comments from epilepsy-related online forums and social media websites that mentioned participants' experiences with AED medication changes (termed passive listening statements) were analyzed and categorized by theme.

Results: All 345 survey participants (270 [78.3%] female; 172 [49.9%] were 26–45 years old) self-reported an epilepsy/seizure diagnosis and were currently taking seizure medication; 263 (76.2%) were taking ≥ 2 AEDs and 301 (87.2%) had ≥ 1 seizure in the previous 18 months. All participants reported a medication change within the previous 12 months (dose increased [153 participants (44.3%)], medication added [105 (30.4%)], dose decreased [49 (14.2%)], medication removed [38 (11.0%)]). Improving seizure control (247 [71.6%]) and adverse events (109 [31.6%]) were the most common reasons for medication change. Primary emotions most associated ($\geq 10\%$ of participants) with an AED regimen change were (before medication change; during/after medication change) hopefulness (50 [14.5%]; 43 [12.5%]), uncertainty (50 [14.5%]; 69 [20.0%]), and anxiety (35 [10.1%]; 45 [13.0%]), and were largely due to concerns whether the change would work (212/345 [61.4%]; 180/345 [52.2%]). In the text analysis segment aimed at validating the survey, 230 participants' passive listening statements about medication titration were analyzed; additional seizure activity during dose titration (93 [40.4%]), adverse events during titration (71 [30.9%]), higher medication dosages (33 [14.3%]), and drug costs (25 [10.9%]) were the most commonly noted concerns.

Conclusion: Although the emotional well-being of patients with epilepsy is complex, our study results suggest that participants report their emotional well-being as negatively affected by changes in AED regimen, with most patients reporting uncertainty regarding the outcome of such a change. Future research is warranted to explore approaches to alleviate patient concerns associated with AED medication changes.

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1. Introduction

Patient emotions may play a vital role in communication and satisfaction with the patient–clinician relationship and in adherence to treatment regimens. Owing to the broad availability of medical

information via the Internet, patients are more informed about their medical condition and treatments than previous generations, prompting a change in the nature of the patient–physician relationship [1–3]. Indeed, patients are becoming more involved in making decisions and managing their disease [4,5], which is dependent upon a solid partnership with their physician. However, evidence suggests that a division exists between physicians and their patients in the importance of different aspects of disease treatment and management [5,6]. In one survey, two-thirds of patients versus one-third of physicians reported avoiding depression, anxiety, and treatment-related behavior changes as important considerations in making treatment decisions [5]. Although half of patients rated reducing the titration period and changes to the

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treatment plan owing to adverse events as important factors in treatment decisions, less than 20% of physicians rated these as important factors. However, both patients and physicians regarded reducing seizure frequency and severity as the most important aspects of treatment [5].

An improved physician–patient dynamic may foster better assessment of patient emotions and perceptions of antiepileptic drug (AED) use, which may impact the treatment adherence so critical for seizure control. In one study, nonadherence to AED therapy was influenced by patient doubts regarding the need for AEDs, negative perceptions of AEDs, and concerns about adverse events [7]. In another study, the majority of surveyed patients blamed forgetfulness for medication nonadherence, while physicians overwhelmingly attributed nonadherence to poor tolerability or patient complacency [6]. Further, intentional nonadherence has been described in patients with chronic conditions, with nonadherence commonly attributed to feeling good and deciding not to dose, or a fear of side effects [8]. Because emotions are intrinsically involved in an individual's decision-making [9] and treatment adherence requires daily decision on the patient's part, addressing patient emotions that may hinder AED titration may help remove barriers to adherence. Ultimately, a better understanding of patient considerations, perceptions, and emotions may help improve the discussion between patients and their physicians, leading to improved treatment outcomes.

Modification to AED regimens often require a titration period that differs depending upon the individual AED and the titration approach (e.g., titration of a new AED to full dose before tapering the first AED, or simultaneously titrating and tapering AEDs [10]). During this titration period, the physician and patient must once again evaluate the benefits of the new medication versus potential side effects. In addition to side effects, the possibility of seizures occurring during AED changes may also be concerning for patients during this timeframe. Changing AED treatment indicates suboptimal seizure control or unacceptable side effects, and changes to optimize AED treatment introduces a new period of uncertainty to the patient as to whether the new treatment will help them achieve seizure control. Although AED treatment changes may negatively affect patients' quality of life [11], patients' emotions regarding an AED regimen change are not well explored, and represents a possible opportunity for addressing patient needs. Additionally, understanding patient emotions during AED treatment changes may better explain other reasons for nonadherence, whether intentional or unintentional, that are typically attributed to forgetting or adverse events. Accordingly, the objective of this survey-based study was to better understand the effect of AED change and dose titration on epilepsy patients' emotional well-being as well as their perceptions during this period of change.

2. Methods

2.1. Patient survey

This study was an open, prospective, cross-sectional survey of adult members with epilepsy from the Epilepsy Advocate disease-state patient community. This online community (www.epilepsyadvocate.com; supported by UCB Pharma) provides patients and their families with an open forum for epilepsy-related information, patient blogs, social networking opportunities, and links to other support sources. An invitation to participate in the survey was posted to the Epilepsy Advocate Facebook page (i.e., "Have you and your physician ever modified your medication plan? We are looking for your perspective on the emotions and mindsets you experienced during a proposed medication change.") with a link to the survey. Names, Facebook IDs, or other personally identifiable information (e.g., e-mails) were not collected. Each respondent provided informed consent, and all responses were automatically captured and tabulated by SurveyMonkey® (SurveyMonkey

Inc, Pala Alto, CA, www.surveymonkey.com). Surveys were completed from September 4, 2015 to October 30, 2015.

Clinical trial experts and a clinical psychologist developed and evaluated the survey based on prior experience, and incorporated guidance for reporting of online surveys [12]. The survey consisted of 31 multiple choice questions that focused on patient experiences and emotions before and during/after the patient's most recent AED medication change in the past 12 months (e.g., change in AED dose or drug, reason for change, duration of change, seizure activity, communication with the clinician, emotions experienced and positivity/negativity) as well as patient demographics and epilepsy characteristics (e.g., age, sex, insurer, number of AEDs, time since diagnosis). The survey did not capture time from the most recent AED change, but all changes were to have occurred in the prior 12 months. All questions about emotion were balanced in terms of variety and valence, a common dimension of emotions (positivity or negativity) used to explain behavior [13]. Emotions were selected based, in large part, on Plutchik's theory of emotions [14]. For comparison purposes, emotion terms were operationally grouped into basic emotion groups as follows (primary emotion terms in parentheses): anticipation (confident, intrigued, optimism), trust (certain, compliant), joy (courageous, eager, hopeful), anger (disbelief, resistant), sadness (anxiety, hopelessness, worry), distrust (afraid, fear, hesitant, uncertain), and none. Anticipation, joy, and trust were considered as having positive valence, while anger, sadness, and distrust were attributed negative valence. Valence (degree of positivity or negativity) is an integral aspect of emotion research [15–17] used to evaluate if something is perceived as helpful or harmful, and was assessed with respect to the primary emotion reported. To confirm assignment of emotion terms (and by extension, basic emotion groups) as being positive or negative, emotion terms were weighted by reported valence (1 = very positive, 2 = slightly positive, 3 = neutral, 4 = slightly negative, 5 = very negative; Supplementary Table 1). Positive or negative emotion groups were expected to be consistent with emotion research [14]. The reason for the emotion before and during/after the medication change also was assessed. Antiepileptic drugs categorized as sodium-channel blocking [SCB(+)] AEDs were carbamazepine, lamotrigine, lacosamide, oxcarbazepine, and phenytoin; non-sodium-channel blocking [SCB(–)] AEDs were levetiracetam, perampanel, topiramate, and divalproate. Antiepileptic drugs with mood-stabilizing properties were those approved by the US Food and Drug Administration for the treatment of bipolar disorder (carbamazepine, lamotrigine, and sodium valproate).

2.2. Passive listening text analysis

In an effort to assess the generalizability of the patient survey findings, a passive listening text analysis was undertaken to extract data from online sources outside of the Epilepsy Advocate community. IMS Health™; Nexxus™ Social Media used longitudinal tracking of patient data on social media platforms to ascertain epilepsy status and extract conversations related to the terms dose, doses, dosage, titrate, or titration in the context of epilepsy or epileptic seizures. Conversations were cross-referenced between websites to ensure epilepsy status. Results were qualitatively analyzed to produce a set of comments related to titration aspects of AED treatment. A set of categorical filters specific to emotional, physical, and general health, adapted from the Quality of Life in Epilepsy Inventory-31 (QOLIE-31) questionnaire [18], was used to probe the final dataset. Questions from the QOLIE-31 were selected based upon applicability to the dose titration phase and probability of being addressed in social media data; in some cases, language was slightly modified based on the patient lexicon and for ease of understanding. An additional category concerning financial issues due to drug expense was included. Based on the information provided in the subject statements, each question was assigned a categorical answer of "Yes," "No," or "Not mentioned." Patients' experiences with the medication change process within emotional, physical, and general

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