Epilepsy & Behavior 63 (2016) 20–28

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

PatientsLikeMe® Online Epilepsy Community: Patient characteristics and predictors of poor health-related quality of life

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ARTICLE INFO

Article history:
Received 6 May 2016
Revised 6 July 2016
Accepted 24 July 2016
Available online xxxx

Keywords:
Social media
Patient networking sites
Epilepsy
Health-related quality of life

ABSTRACT

Objective: The online PatientsLikeMe® Epilepsy Community allows patients with epilepsy to record, monitor, and share their demographic, disease, and treatment characteristics, providing valuable insights into patient perceptions and understanding of epilepsy. The objective of this retrospective analysis was to characterize the profile of users and their disease and identify factors predictive of poor health-related quality of life (HRQoL), while assessing the platform's potential in providing patient-reported data for research purposes.
Methods: Data recorded (January 2010–November 2011) by Epilepsy Community members, with an epilepsy diagnosis and who reported >1 seizure, included the following: sociodemographic and disease characteristics, treatments, symptoms, side effects perceived as medication-related, seizure occurrence, and standardized questionnaires (Quality of Life in Epilepsy Inventory [QOLIE-31/P], EuroQoL 5-Dimensions Scale, 3 Levels [EQ-5D-3L], and Hospital Anxiety and Depression Scale [HADS]). Univariate and multivariate logistic regressions were conducted to identify predictors of poor HRQoL.
Results: During the study period, the Epilepsy Community comprised 3073 patients, of whom 71.5% were female, had a mean age of 37.8 years, and had a mean epilepsy duration of 17.7 years. The most frequently reported moderate/severe symptoms (n = 2135) included memory problems (60.2%), problems concentrating (53.8%), and fatigue (50.0%). Medication-related side effects (n = 639) included somnolence (23.2%), fatigue (17.2%), and memory impairment (13.8%). The QOLIE-31/P scores (n = 1121) were significantly worse in patients who experienced a recent seizure. For QOLIE-31/P, highly predictive factors for poor HRQoL included the following: mild/moderate problems concentrating, depression, memory problems, treatment side effects, occurrence of tonic–clonic seizures, and epilepsy duration ≤1 year. For EQ-5D-3L, highly predictive factors for poor HRQoL included the following: pain, depression, and comorbidities. Patients on newer AEDs were less likely to report poor HRQoL (QOLIE-31/P).
Significance: These findings move further towards supporting the feasibility and usefulness of collecting real-world, anonymized data recorded by patients online. The data provide insights into factors impacting HRQoL, suggesting that a holistic treatment approach beyond seizure control should be considered in epilepsy.

1. Introduction

Health-related quality of life (HRQoL) describes an individual's self-perception of well-being, which includes physical, mental, emotional, and social domains of life [1,2]; HRQoL focuses on the impact health status has on quality of life. In epilepsy, the occurrence of seizures has a negative impact on the HRQoL of those living with epilepsy [3], with higher seizure frequency and severity resulting in decreased patient HRQoL [4]. Other factors also contribute to poor HRQoL among patients with epilepsy, such as the occurrence of side effects associated with

Abbreviations: AED, antiepileptic drug; EQ-5D-3L, EuroQoL 5-Dimensions Scale, 3 Levels; HADS, Hospital Anxiety and Depression Scale; GTC, generalized tonic–clonic; HRQoL, health-related quality of life; NEWQOL, Quality of Life in Newly Diagnosed Epilepsy Instrument; PRO, patient-reported outcome; QOLIE-31/P, Quality of Life in Epilepsy Inventory; SD, standard deviation.

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http://dx.doi.org/10.1016/j.yebeh.2016.07.035
1525-5050/

antiepileptic drug (AED) treatment [5]; psychiatric comorbidities, such as depression and anxiety [3,6]; the perceived stigma of epilepsy [7]; and a reduced level of independence (e.g., not being able to drive) [8]. Improving the HRQoL of patients with epilepsy is an important component of contemporary disease management strategies [9], in addition to treating or preventing the occurrence of seizures.

Disease management and patient support strategies have evolved significantly over the past decade, with many patients now taking a more active role in collaborating with their healthcare provider(s) [10,11]. The popularity of networking sites, online communities, and virtual forums, where patients can discuss their health concerns and exchange information, is growing, especially for those living with chronic diseases [11]. PatientsLikeMe® (http://www.patientslikeme.com) is an online health data-sharing platform for patients with life-changing diseases. The main goals of the website are to provide patients with the tools to record, track, and share their disease characteristics and outcomes; to help patients learn how to improve their care through peer-to-peer interactions; and to enhance understanding of how the disease and its treatment can potentially impact their lives [10,11]. The PatientsLikeMe Epilepsy Community, launched in the United States in January 2010, was developed in partnership with UCB Pharma. The perceived benefits reported by patients using the system include the ability to connect with others experiencing the same symptoms, having a better understanding of their seizures, learning more about symptoms or treatments [11], and improvement in patient self-management and self-efficacy [12].

Through this research, data collected from PatientsLikeMe Epilepsy Community members were utilized to help characterize demographic and epilepsy characteristics in this patient population, including symptoms and medication-related side effects, and to identify factors predictive of poor HRQoL. In addition, the potential of the platform for collecting patient-reported data suitable for research purposes was assessed, as were the validated and standardized instruments used to record HRQoL-related data from patients with epilepsy.

2. Methods

2.1. Study population

PatientsLikeMe Epilepsy Community members, who logged in to the website between January 2010 and November 2011, reported a diagnosis of epilepsy, and had experienced more than one seizure during their lifetime, were included in the analysis. Initially, the community was only accessible to users in the United States; however, from April 2011, it became available worldwide (English language only). Members and users of the site became aware of the opportunity to join PatientsLikeMe through online advertising (e.g., on Google and Facebook), media partnerships, press coverage, word of mouth, and physician referral.

All members of the PatientsLikeMe Epilepsy Community agreed to be contacted for research as a condition of joining the community and were free to opt in or out, allowing for them to only disclose information they were willing to share. It was made clear that there would be no adverse consequences if members elected not to participate.

Institutional review board approval was not sought because of the noninterventional nature of the analysis.

2.2. Data collection

Patients (or their caregiver [parent or guardian]) were able to record information on sociodemographic characteristics and a range of epilepsy and treatment-related characteristics. Patients could record the occurrence and severity of symptoms (none, mild, moderate, severe) using a predefined checklist (Supplementary Fig. 1A). The symptom checklist was developed by a panel of epilepsy experts and included symptoms considered likely to occur frequently among patients with epilepsy (anxiety, depression, fatigue, headache, insomnia, memory problems, pain, problems concentrating, and somnolence). Patients could also document their treatment history and current treatment(s) and specify any side effects they perceived to be related to their treatment (medication-related side effects; assessed as mild, moderate, or severe) (Supplementary Fig. 1B). Side effects were not prespecified. However, a drop-down box listing side effects previously reported by users of the PatientsLikeMe site was available and appeared once the user began typing in his/her side effects. The user could also include verbatim side effects where applicable. Side-effect terms were classified according to the Medical Dictionary for Regulatory Activities coding [13] version 14.1. In line with adverse event reporting regulations, a pharmacovigilance system was employed during the data collection period to identify, record, evaluate, and report medication-related side effects attributed to UCB products.

Patients also had the opportunity to complete and review their information for a number of validated, standardized patient-reported outcome (PRO) instruments, namely, the Quality of Life in Epilepsy Inventory (QOLIE-31/P) [14], the Hospital Anxiety and Depression Scale (HADS) [15], and the EuroQoL 5-Dimensions Scale, 3 Levels (EQ-5D-3L) [16]. These instruments were selected as QOLIE-31/P is the most widely used assessment of HRQoL in epilepsy trials, HADS captures varying levels of anxiety and depression and is widely referenced in the literature, and the EQ-5D-3L is in widespread use for health technology assessments by agencies such as the National Institute for Health and Care Excellence (NICE). The QOLIE-31/P is an epilepsy-specific HRQoL instrument, which comprises 30 items grouped into seven multi-item subscales, assessing seizure worry, overall quality of life, emotional well-being, energy/fatigue, cognitive function, medication effects, and social function. It requests that participants take into consideration the last 4 weeks when responding. It also includes an additional, overall health status item [14,17] not included in the total score calculation. The QOLIE-31/P total score is calculated as a weighted average of the subscale scores and ranges from 0 to 100, with 100 representing the best HRQoL [14,17]. The HADS instrument assesses the presence and severity of anxiety and depression and requests that the previous week be considered when responding. It consists of 14 items, scored on a 4-point severity scale. An anxiety score and a depression score are calculated, each ranging from 0 to 21, with levels of anxiety and depression classified as follows: normal (0–7), mild (8–10), moderate (11–14), and severe (15–21) [15]. The EQ-5D-3L is a generic instrument assessing health status that enables comparison with other diseases [16]. It includes five items covering key dimensions of life, including the following: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression, which are rated as follows: no problem, some/moderate problems, or extreme problems [16]. These dimensions are used to determine the patient's health state, which is mapped to a utility score anchored at 0 and 1, with 1 representing full health [16]. The overall health status item is measured on a visual analog scale from 0 to 100, with 100 representing full health. The EQ-5D-3L instrument requests that participants take into consideration 'your own health state today' when responding. The EQ-5D-3L utility score was calculated using US weights taken from the general population [18].

Patients were able to update their profile at any time and were asked to complete the battery of PRO instruments at least once. Before the completion of the PRO instruments, patients were prompted to update their profile and were required to provide information about their seizure experience during the last 4 weeks (experience/no experience of simple partial, complex partial, or generalized tonic–clonic seizure). The PRO instruments were provided in the following order: QOLIE-31/P, HADS, and EQ-5D, and all questions per page had to be answered in order to progress to the next page or to the next PRO instrument. Data were collected from the first completion of each of the PRO instruments. The results of the PRO instruments completed by each patient were available for the patient to view personally on the PatientsLikeMe