



## Social media in epilepsy: A quantitative and qualitative analysis



Ying Meng<sup>a,b</sup>, Lior Elkaim<sup>c</sup>, Justin Wang<sup>a</sup>, Jessica Liu<sup>a</sup>, Naif M. Alotaibi<sup>a,b,\*</sup>, George M. Ibrahim<sup>a</sup>, Aria Fallah<sup>d</sup>, Alexander G. Weil<sup>c</sup>, Taufik A. Valiante<sup>a,e</sup>, Andres M. Lozano<sup>a,e</sup>, James T. Rutka<sup>a,f</sup>

<sup>a</sup> Division of Neurosurgery, Department of Surgery, University of Toronto, Toronto, Ontario, Canada

<sup>b</sup> Institute of Medical Science, Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada

<sup>c</sup> Division of Pediatric Neurosurgery, Department of Surgery, Sainte Justine Hospital, University of Montreal, Montreal, QC, Canada

<sup>d</sup> Department of Neurosurgery and Pediatrics, David Geffen School of Medicine at University of California, Los Angeles, CA, USA

<sup>e</sup> Krembil Research Institute, Toronto Western Hospital, Toronto, Ontario, Canada

<sup>f</sup> Division of Neurosurgery, Hospital for Sick Children, Toronto, Ontario, Canada

### ARTICLE INFO

#### Article history:

Received 22 March 2017

Revised 21 April 2017

Accepted 22 April 2017

Available online 26 May 2017

#### Keywords:

Epilepsy

Seizure

Facebook

Twitter

Social media

### ABSTRACT

**Background:** While the social burden of epilepsy has been extensively studied, an evaluation of social media related to epilepsy may provide novel insight into disease perception, patient needs and access to treatments. The objective of this study is to assess patterns in social media and online communication usage related to epilepsy and its associated topics.

**Methods:** We searched two major social media platforms (Facebook and Twitter) for public accounts dedicated to epilepsy. Results were analyzed using qualitative and quantitative methodologies. The former involved thematic and word count analysis for online posts and tweets on these platforms, while the latter employed descriptive statistics and non-parametric tests.

**Results:** Facebook had a higher number of pages (840 accounts) and users (3 million) compared to Twitter (137 accounts and 274,663 users). Foundation and support groups comprised most of the accounts and users on both Facebook and Twitter. The number of accounts increased by 100% from 2012 to 2016. Among the 403 posts and tweets analyzed, “providing information” on medications or correcting common misconceptions in epilepsy was the most common theme (48%). Surgical interventions for epilepsy were only mentioned in 1% of all posts and tweets.

**Conclusions:** The current study provides a comprehensive reference on the usage of social media in epilepsy. The number of online users interested in epilepsy is likely the highest among all neurological conditions. Surgery, as a method of treating refractory epilepsy, however, could be underrepresented on social media.

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### 1. Introduction

Epilepsy is one of the most common neurological disorders, affecting over 60 million people of all ages worldwide and is characterized by recurrent, unprovoked seizure activity. Despite the availability of numerous anti-epileptic drugs, up to 35% of the patients have medically refractory epilepsy [1]. Like many other chronic diseases, in addition to the biological manifestations, the cognitive and psychosocial burdens of epilepsy are significant. The societal impact of epilepsy has been well-studied and documented in both print and other traditional media. For example, Steer et al. found a strong correlation between the prevalence of epilepsy and socioeconomic deprivation [2]. Despite these findings, patients' disease experiences in addition to their desired care from the

healthcare system vary greatly [3]. Furthermore, epilepsy similarly remains a condition not well understood and subject to stigmatization by the general public [4].

Social media has become an instrumental part of the increasing number of people's lives worldwide. In 2016, Twitter reported over 313 million active users [5]. Because of the growing patient presence on these sites, healthcare professionals are also more interested and involved in the adoption of social media to gain access to patients and for the delivery of personalized medicine [6]. The number of published, peer-reviewed articles containing both the keywords “social media” and “quality of care,” as documented by the National Center for Biotechnology Information, increased from 139 in 2005 to 780 in 2015. Social media can be utilized for healthcare in a number of different ways, including information dissemination, peer-to-peer communication, research data collection, public opinion assessment, and knowledge generation [7]. On one hand, the advantages of social media as a tool for healthcare include widespread usage, efficiency, and ability to collect real world information from users [8]. On the other hand, the

\* Corresponding author at: Division of Neurosurgery, University of Toronto, 399 Bathurst St., WW 4-427, Toronto, ON M5T 2S8, Canada.

E-mail address: [naif.alotaibi@mail.utoronto.ca](mailto:naif.alotaibi@mail.utoronto.ca) (N.M. Alotaibi).

disadvantages of obtaining data from social media are the inconsistent quality of information obtained in addition to sampling, reporting, and recall bias. Our manuscript aims to assess how social media is used by online users interested in epilepsy and epilepsy-related topics to identify gaps in physician–patient communication and public understanding of specific topics and treatment interventions.

## 2. Methods

### 2.1. Search strategy and platform selection

We performed a comprehensive search on two different social media platforms that are currently ranked as the most utilized networks in online text/media-based communications (Facebook and Twitter) [5,9]. We applied the following search terms separately and in combination to identify Facebook pages and Twitter accounts related to epilepsy: “epilepsy”, “epilepsies”, “epileptic”, and “seizure” [10]. We excluded accounts and pages not exclusively dedicated to clinical epilepsy in a human population (e.g. animal epilepsy disorders or music bands that carry the title “epilepsy”). The search was performed by two independent authors (J.L., N.M.A) in June to August 2016.

### 2.2. Social media metrics and data

We extracted population data from Facebook using the number of “likes” by users and from Twitter using the number of followers. Several metadata variables were collected, including the year in which the account was created as well as the account’s country of origin. We categorized each Facebook page and Twitter account based on its objective or purpose and public titles or account descriptions which were user-generated. The following eight categories: “non-profit foundation”, “business”, “medical center”, “support group”, “research”, “education”, “journals and magazines”, and “events” were initially formulated based on the findings encountered during an initial screening of 100 different titles of various pages and accounts. Pages and accounts were independently categorized by two different authors (J.L., N.M.A) from August to October 2016. Supplementary Table 1 provides examples of each category on Facebook pages or Twitter accounts.

### 2.3. Thematic and word-count analysis of posts and tweets

We extracted the most recent 50 posts and tweets from each account category, as previously described [11]. The number is expected to represent the point at which saturation is reached, where no novel themes emerge from analysis of further data. Each extracted post and tweet were independently evaluated and verified by two authors (L.E., N.M.A.). Posts and tweets were examined using modified thematic analysis, using open and axial coding methods [12]. The open coding method involves sorting posts and tweets into common groups based on shared themes or ideas while axial coding subsequently categorizes all open codes based on even broader overarching themes. For example, posts from users asking about clinical presentation or various treatment options regarding epilepsy would be open coded as “inquiring about symptoms” and “queries regarding treatment”, respectively. The axial code under which these open codes would fall under would be “requesting information.” Both investigators analyzed all the data and generated explanatory codes for general recurring themes until new themes did not continue to emerge from data review, and saturation was reached [13]. Differences in categorization and other discrepancies between the two evaluators were discussed until a consensus was reached. All words from posts and tweets were included for text analysis using a free online application (<http://www.wordclouds.com/>).

### 2.4. Statistical analysis

Descriptive statistics [mean, median, standard deviation, and interquartile range (IQR)] for social media metrics were calculated. In agreement with previous studies describing social media, our metrics were not normally distributed [14,15]. Therefore, non-parametric two-tailed tests were used to evaluate possible variation in the quantity of users between different coded categories (Mann–Whitney U for two groups or Kruskal–Wallis tests for multiple groups). Statistical significance was set at P-values less than 0.05. SPSS version 21 was used to perform all statistical analyses (IBM SPSS Statistics, Chicago, USA).

### 2.5. Ethical considerations

All extracted data utilized and presented in this study were archival, cross-sectional, observational, and obtained from publicly accessible sources without any interaction with social media users with their usernames omitted. Therefore, the present study meets the exclusion criteria of the Canadian Tri-Council Policy Statement for research which necessitates a review by an institutional research ethics board as all data were already publicly available.

## 3. Results

### 3.1. Quantitative analysis

Table 1 list the number of pages and accounts found on Facebook and Twitter related to epilepsy. Facebook had a higher number of pages (840) and total users (3 million) compared to Twitter (137 accounts and 327,917 user), however, no significant difference exists between the medians of both platforms ( $P = 0.056$ ). The USA was the most common country of origin of all pages seen on Facebook (35%), followed by Canada (6%). Almost 40% of Facebook pages did not list the country of origin. The most common page category found on Facebook was “non-profit foundations” with 400 pages (47%) followed closely by “patient and caregiver support groups” (36%). Only 4% of pages were run by certified medical centers with dedicated treatments for epilepsy. Similarly, pages dedicated to “business” in epilepsy which promoted services and/or products to assist patients (e.g., medication calendars, special nursing care, cannabis) comprised only 4% of all pages. There were significant differences in number of users between page categories ( $P < 0.0001$ ) with “non-profit foundations” having the highest median user number (781 users).

Similar findings were seen on Twitter. Again, the most common country of origin for Twitter accounts was the USA (52%), followed by Canada (12%). Twitter accounts of “non-profit foundations” were also the most common (80%). There were no significant differences in number of users between categories on Twitter.

Fig. 1 shows the time-trend of newly established pages and accounts on Facebook and Twitter, respectively. There were 18 pages or accounts that did not mention time creation. The year 2013 had the highest numbers of accounts. The total number of accounts on Facebook and Twitter increased dramatically by 100% from 2012 to 2016 (280 accounts prior to 2012 vs. 679 after 2012).

**Table 1**

Distribution of users in pages and accounts dedicated to epilepsy across Facebook and Twitter, respectively.

Social media platform	No. of pages/accounts	Mean (SD) of no. of users	Median (IQR) of no. of users	Total no. of users
Facebook	840	3778 (17,194)	645 (219–1630)	3,170,454
Twitter	137	2411 (7483)	1018 (361–1834)	327,917

Abbreviations used: SD: standard deviation, IQR: inter-quartile range.

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