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Brief Communication

Online behavior of people visiting a scientific website on epilepsy

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ABSTRACT

We investigated the online behavior of Internet users consulting the website of the Italian Chapter of the International League Against Epilepsy (Lega Italiana Contro l'Epilessia [LICE]). We obtained the visualization statistics of the LICE website using AWStats (https://awstats.sourceforge.io/) and Google Trends (https://trends.google.com/trends/), and compared the statistics of years 2010, 2014, and 2017. The following variables were analyzed: number of unique visitors and visits, visit duration, the day of week and rush hours, most downloaded documents, most viewed pages, keyphrases and keywords used for online searches, origins of searches, and geographic trends of Google searches related to the LICE. The total numbers of unique visitors, visits and page views remained quite stable over time. Most visits (70 to 76.7%) lasted less than 30 s. The most frequent keyphrases and keywords used for online searches were related to clinical guidelines and driving license. Among the most frequently downloaded documents were general guides on epilepsy. The pages with the list of epilepsy centers endorsed by the LICE and those with the list of LICE guidelines were among those most frequently viewed, together with educational videos. Most users directly accessed the website without being referred from external links. No information on geographic origin of Google searches was available. The visualization statistics suggested two distinct populations of visitors. The first one is likely represented by physicians who seek specialist information on diagnosis and management of epilepsy, including guidelines. The second population is represented by lay people who seek accessible and easily comprehensible information to better understand epilepsy and know which centers are best for its management.

1. Introduction

The Internet has become an increasing source of health information. The availability of data generated by online searches on health-related information has led to a new field of epidemiology, called infodemiology (information epidemiology) [1] or digital epidemiology. The aim of infodemiology is to study how health information is provided and accessed on the Internet, in order to inform public health and public policy [1,2]. As follows, infodemiological analyses can: 1. explore possible associations between the Internet searches and epidemiology (prevalence, incidence, and/or spatiotemporal distribution) of a specific disease [3–6], 2. identify unmet information needs among the Internet users [7], and 3. assess how health information is conveyed and accessed on the Internet [8–10].

Scientific societies can efficiently provide online information on epilepsy. In April 2009, the Italian Chapter of the International League Against Epilepsy (Lega Italiana Contro l'Epilessia [LICE]) inaugurated a website, written in Italian, with the aim of providing accessible information on epilepsy (http://lice.it/).

The aim of this infodemiological study was to investigate the online behavior of the Internet users consulting the LICE website.

2. Methods

We compared the visualization statistics of years 2010 (the year following inauguration), 2017 (respectively, the first and latest year for which data for all months were available at the time of the study), and 2014 (chosen as a middle year between the other two). We obtained

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the visualization statistics of the LICE website using AWStats (https://awstats.sourceforge.io/). AWStats is a free software that creates server statistics reports based on the rich data contained in server logs. Details on its features are available online at https://awstats.sourceforge.io/docs/awstats.pdf.

The following variables were analyzed:

1. Number of unique visitors per year and month. A unique visitor is a person or computer (host) that has made at least request to a web server for a file, including web pages on the website of interest during the prespecified period. If this user makes several visits during this period, it is counted only once. Visitors are tracked by Internet Protocol (IP) address. Hence, if multiple users are accessing the website from the same IP, they are counted as a single unique visitor.
2. Number of visits made by all visitors per year and month.
3. Number of "pages" viewed by visitors per year and month.
4. Session duration: the time spent by a visitor on the website for each visit.
5. Days of week and rush hours of visits.
6. Countries of host visitors with the highest number of page views.
7. Most downloaded documents.
8. Most viewed pages.
9. Most frequent keyphrases and keywords used for online searches, which eventually directed the Internet users to the LICE website.
10. Origin of searches that eventually led to the LICE website (direct address/bookmark/link in email; links from an Internet search engine; links from an external page (other web sites except search engines)).

The potential reasons accounting for the differences in visualizations between the years were narratively analyzed and discussed.

Furthermore, we used Google Trends (accessed online at: https://trends.google.com/trends/) to explore the temporal and regional trends in Google searches related to the LICE. We entered the search terms "LICE epilessia" and "Lega Italiana contro l'Epilessia" in the *Explore* bar of Google Trends and analyzed data on "Interest over time" from January 1, 2004 to November 1, 2018 provided as Google Trends charts and raw data. We also analyzed temporal trends in Google searches for years 2010, 2014, and 2017. We also compared the relative volumes of Google searches related to the LICE with those on two other Italian neurological Societies, the Italian Society of Neurology (Società Italiana di Neurologia [SIN]) and the Italian Association for Multiple Sclerosis (Associazione Italiana Sclerosi Multipla [AISM]), by entering the following search terms: "SIN neurologia", "Società Italiana di Neurologia", "AISM Sclerosi multipla", and "Associazione Italiana Sclerosi Multipla". We also compared the Google searches related to the LICE with the searches on epilepsy by entering the search term "epilessia" (epilepsy).

Besides exploring interest over time, we analyzed in which Italian regions and cities the above mentioned search terms were most popular during the specified time frames, both using the charts on regional trends in Google searches and raw data provided by Google Trends.

In Google Trends, search results are proportionate to the time and location of searches. The following adjustments are made: "Each data point is divided by the total searches of the geography and time range it represents to compare relative popularity. Otherwise, places with the most search volume would always be ranked highest. The resulting numbers are then scaled on a range of 0 to 100 based on a topic's proportion to all searches on all topics" [11]. Searches made by very few people are excluded; hence, search terms with low volume appear as "0".

Data on temporal trends in Google searches should be interpreted considering that "numbers represent search interest relative to the highest point on the chart for the given region and time. A value of 100 is the peak popularity for the term. A value of 50 means that the term is half as popular. A score of 0 means there was not enough data for this term" [11]. Data on geographic trends in Google searches are "calculated on a scale from 0 to 100, where 100 is the location with the most popularity as a fraction of total searches in that location, a value of 50 indicates a location which is half as popular. A value of 0 indicates a location where there was not enough data for this term" [11]. Of note, a higher value means a higher proportion of all queries, not a higher absolute query count. Hence, a very small country where 80% of the queries are for a certain term will get twice the score of a giant country where only 40% of the queries are for the same term [11].

3. Results

The total numbers of unique visitors remained quite stable over time (80,901 in 2010; 67,785 in 2014; 85,617 in 2017), as well as the total number of visits and pages viewed by visitors (Table 1). Most of the users visited the LICE website from Monday to Friday, from 8.00 a.m. to 11.00 p.m. (Supplementary material, Table 1). Over the time period of the study most visits (70 to 76.7%) lasted less than 30 s, whereas only 0.7 to 0.9% lasted more than 1 h. The average session duration was 194 to 205 s, and remained substantially unchanged over the years (Supplementary material, Table 2). As expected, Italy was the country with the highest frequency of page views (Supplementary material, Table 3).

No document was downloaded in 2010. In 2014, the most downloaded document (593,924 downloads) has been the booklet devoted to epilepsies written by some LICE neurologists, followed by the abstract proceedings of the 2012 LICE congress that focused on the discussion of clinical cases (21,099), and the LICE recommendations for the use of electroencephalogram (EEG) and activation procedures (10,522). In 2017, the most downloaded documents have been the practical guide for the management of patients with epilepsy (21,660), the LICE recommendations for the use of EEG and activation procedures (10,978), and the LICE booklet devoted to epilepsies (9669) (Supplementary material, Table 4).

In 2010, the most frequently viewed pages were those providing educational information on epilepsy and activities of the LICE using short videos (4 videos; total: 51,866 views). In 2014, the most viewed pages were those reporting the list of epilepsy centers endorsed by the LICE (13,404), the list of LICE guidelines (9302), and the link to the LICE booklet devoted to epilepsies (8905). Three years later (2017), the page with the list of epilepsy centers endorsed by the LICE (15,720) and that with the list of LICE guidelines (10,121) remained the most frequently accessed (Supplementary material, Table 5).

The most common keyphrases and keywords used for online searches, which eventually directed the Internet users to the LICE website, were related to clinical guidelines and driving license (Supplementary material, Tables 6 and 7).

Most connections to the LICE website originated from direct address/bookmark/link in email (49% in 2010; 61.6% in 2014; 65.9% in 2017); Google was the most frequently used Internet search engine used to connect to the LICE website (68,916 links to LICE pages in 2010; 59,548 in 2014; 66,731 in 2017) (Supplementary material, Table 8).

Over time, the search volume of Google searches related to the LICE was constantly much lower than that for searches on "epilessia" (epilepsy) (Supplementary material, Table 9). It was also constantly lower than search volumes related to the Italian Society of Neurology and the Italian Association for Multiple Sclerosis (Supplementary material, Table 10).

The relative volume of Google searches related to the LICE was too low to enable a geographic analysis. Data on geographic trends in Google searches related to the term "epilessia" (epilepsy) are reported in Supplementary material, Table 11. At regional level, the highest search volume for this term came from Central and South Italy; most searches were done in capital cities of regions (e.g., Florence, Milan, Rome).

Table 1
Total number of unique visitors, visits, and pages viewed by visitors per year of interest (2010, 2014, 2017) and month.

Month	Unique visitors 2010	Unique visitors 2014	Unique visitors 2017	Number of visits 2010	Number of visits 2014	Number of visits 2017	Number of pages viewed 2010	Number of pages viewed 2014	Number of pages viewed 2017
Jan	8093	5864	8229	10,204	8194	12,418	37,296	33,476	47,131
Feb	6662	4939	9626	8396	6730	13,735	37,696	37,707	87,980
Mar	7445	6013	8279	9522	8682	12,363	39,633	31,195	32,920
Apr	7013	5582	6752	8811	7971	10,818	36,660	31,347	28,512
May	7615	7248	6592	9694	10,113	10,582	41,836	43,270	25,290
Jun	6118	5070	6398	7470	7074	10,663	26,798	37,129	28,560
Jul	5285	4842	6100	6462	6663	9178	22,737	25,463	21,203
Aug	5145	3835	5641	6251	5115	8485	23,893	18,114	18,790
Sep	6780	5920	6652	8450	7688	9904	31,932	26,128	35,434
Oct	6890	6597	8075	8327	9098	11,794	30,476	34,372	36,287
Nov	7873	6400	7076	9572	8434	10,581	36,106	31,774	30,453
Dec	5982	5475	6197	7538	7186	9292	24,715	37,794	30,354
Total	80,901	67,785	85,617	100,697	92,948	129,813	389,778	387,769	422,914

4. Discussion

In this study, we investigated the online behavior of the Internet users consulting the official website of the Italian scientific society devoted to epilepsy. So far, no similar study has been conducted.

The total numbers of unique visitors, visits, and page views remained quite stable over time, without major differences between 2010, 2014, and 2017. The number of unique visitors per year hugely exceeded that of LICE members, who are about 900, and clearly indicates that the website is mainly consulted by other physicians and lay people.

Interestingly, most visits lasted less than 30 s, and the average session duration was less than 4 min. The very short duration of page visits reflects the "hit-and-run" approach of most online information consumers, and emphasizes the importance of conveying information incisively and briefly to capture and keep the reader's attention.

Among the most frequently downloaded documents there were two general guides on epilepsy. One was a patient-oriented booklet, which was published in 2014 with the aim of providing patient-targeted high-quality, free, and easily accessible information. Of note, the booklet was downloaded a huge number of times (593,924) and the webpage with the link to this booklet was one of the most viewed in 2014. The second document was the practical guide for the management of patients with epilepsy, which was targeted to neurologists without a specific expertise in epilepsy and to general practitioners. The LICE recommendations on the use of EEG and activation procedures were also frequently downloaded in 2014 and 2017. Furthermore, the pages with the list of LICE guidelines and epilepsy centers endorsed by the LICE were among those most frequently viewed in 2014 and 2017.

Interestingly, in 2010, the most viewed pages did not contain written information, but short educational videos on epilepsy. Of note, the reason why these videos were not among the most popular (top 10) visualized contents in the remaining years can be explained by the fact that they were subsequently removed from the main page of the LICE website, hence becoming more difficult to retrieve. The use of videos has proved effective in improving knowledge and reducing stigma regarding epilepsy [12,13], and can convey information in an effective way also to people with low literacy skills (including children and patients with cognitive or intellectual disability) [8]. Some studies have shown that videos are among the preferred sources of online health-related information [14–16]. However, the accuracy and reliability of information conveyed by online videos is often low. For instance, videos on epileptic seizures and epilepsy available on Youtube can be inaccurate and misleading [17–19], carrying the risk of promoting unscientific therapies and disseminating unreliable information.

Most connections to the LICE website originated from direct address/bookmark/link in email rather than from links from an Internet search engine. This suggests that most people who visit the ILAE website are already aware of its existence, and do not come across it by surfing around various sites on the Internet. For instance, it is possible that Internet users visit the LICE website after having received information about it by channels other than the Web (e.g., during neurological visits at one of the LICE centers active throughout the entire Italian territory). However, definite conclusions cannot be drawn, because so far no study has examined where most Italians receive their health information concerning epilepsy in general and the activities of the LICE in particular.

In the present study, we tried to understand where the searches related to the LICE originate. Since AWStats does not enable this type of analysis, we used Google Trends, to explore which Italian regions and cities had the highest volume of Google searches related to the LICE. Unfortunately, the relative volume of searches was too low to enable a geographic analysis. However, adjusted data on geographic trends in Google searches related to the term "epilessia" (epilepsy) reveal that most searches come from capital cities of regions (e.g., Florence, Milan, Rome). This suggests that the majority of searches come from population centers rather than from rural areas.

Most indirect searches eventually connecting to the LICE website were conducted using Google. It is interesting to note that, over time, the relative volume of Google searches related to the LICE were lower than those for the Italian Society of Neurology and the Italian Association for Multiple Sclerosis. This may be due to different degree of awareness of these neurological societies by Internet users; however, as previously demonstrated by epidemiological studies, the volume of Google searches may only partly reflect the epidemiology of a certain disease, and may be influenced by news about famous people suffering from that condition, or from public perception and attitudes (including patient's fears and worries) about it [20–22].

The Internet is one of the most frequently accessed sources of information for patients with epilepsy, including social media platforms such as Facebook and Twitter [23]. This has been confirmed by recent studies. A UK nationwide survey in 2007, of men with epilepsy revealed that the Internet was the third choice for obtaining epilepsy-related information after the general practitioner and the neurologist [24]. A further study showed that 54% of patients recruited from epilepsy clinics used the Internet to guide self-management of their epilepsy [25]. Results of these surveys should be considered together and integrated with findings of infodemiological studies.

However, unlike surveys, in infodemiological studies the unit of observation is the population and not the individual. They should be considered ecological studies, and their observational results should be interpreted with caution, considering that several factors influence the search volume and the type of sought information [9,26–28]. Furthermore, the Internet represents a sort of a "black box" which can be explored only partly [29]. Hence, detailed statistics on search trends and volumes over time can at most hint at the ultimate reasons of the online searches which, however, cannot be established with precision [29,30].

The findings from our study suggested the existence of two distinct populations visiting a scientific website on epilepsy. The first one is likely represented by physicians (neurologists with expertise on epilepsy, general neurologists, general practitioners, or other specialists) who consult the website to obtain information on diagnosis and management of epilepsy, including guidelines. The second population is represented by lay people (patients, caregivers, other subjects with interest for epilepsy) who seek accessible and easily comprehensible information (including non-written information conveyed through videos) to better understand what epilepsy is and also which centers are specialized in its management.

It is therefore advisable to try to convey information online using different communicative strategies aimed at addressing the specific informative needs of the different Internet users.

Unfortunately, the average health literacy in general population is low. Italy suffers from particularly low average levels of literacy skills, with only 47% of adults aged 16 to 65 who can at most locate a single piece of information in a text that is identical or synonymous to the information in the question [31]. Even if they can read, adults at this literacy level may be unable to apply this skill to simple tasks, such as determining the correct amount of medicine to take from information printed on the package [31]. Low literacy level may reduce patients' abilities to understand health information, follow medical instructions, take drugs correctly, and learn about disease prevention [32]. People with epilepsy are at high risk of low health literacy levels, and may therefore encounter difficulties in adequately understanding written information. Previous studies have shown that websites providing health-related information, including Wikipedia, are not easily accessible to patients or their families, in terms of readability; this has been demonstrated not only for websites providing information on epilepsy [8], but also for online sources on other diseases [10,33–36].

Epilepsy-related information targeted to patients and lay people should therefore be conveyed with high readability. Some recommendations could be followed to improve the usability of health information [8,37–39]. Informative materials should be prepared taking into consideration the age, social status, education, language and literacy skills, as well as likely potential cognitive deficits of the targeted users. Members of the intended user group should be actively involved in planning informative materials to determine what information they need to know, how they will use it, and how readable it is. Readability should be tested before definite publication. Plain language should be used and written messages should be supplemented with visuals like simple drawings. Simple words and short sentences should be preferred over polysyllabic words and long complex sentences. Color coding of tabular information, images and videos should be further used to enhance the material and improve the reader's comprehension. Finally, written communication should look easy to read, for instance avoiding italics and fancy scripts, using headings and bullets to break up the text and leaving white space around margins.

5. Conclusions

Our study suggests that both physicians and lay people are likely to consult scientific websites on epilepsy, and the kind of information they look for is probably different. Hence, different strategies should be adopted to convey appropriate information and address the specific information needs of the different Internet users. Low health literacy is a widespread issue, which needs to be taken into account when developing patient-targeted materials to serve a broader audience. Improving the readability of online information is essential to increase knowledge and improve attitudes of the general population and patients toward epilepsy.

We have demonstrated that it is possible to derive meaningful information from a scientific society website, using the above methodology, which can allow insights into the user behavior, as well as offering opportunities for development of further strategies for how to target users in a more direct and meaningful way. This is essential to allow webpages to remain relevant to their users.

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Conflicts of interest

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