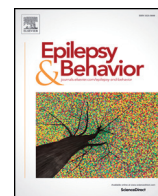


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Brief Communication

Italian Wikipedia and epilepsy: An infodemiological study of online information-seeking behavior

Francesco Brigo ^{a,b,*}, Simona Lattanzi ^c, Giorgia Giussani ^d, Laura Tassi ^e, Nicola Pietrafusa ^f, Carlo Andrea Galimberti ^g, Raffaele Nardone ^{b,h}, Nicola Luigi Bragazzi ⁱ, Oriano Mecarelli ^j

^a Department of Neurosciences, Biomedicine and Movement Sciences, University of Verona, Verona, Italy

^b Hospital Franz Tappeiner, Department of Neurology, Merano, Italy

^c Marche Polytechnic University, Neurological Clinic, Department of Experimental and Clinical Medicine, Ancona, Italy

^d IRCCS-Istituto di Ricerche Farmacologiche 'Mario Negri', Laboratory of Neurological Disorders, Department of Neuroscience, Milan, Italy

^e Niguarda Hospital, 'Claudio Munari' Epilepsy Surgery Centre, Milan, Italy

^f Bambino Gesù Children's Hospital, IRCCS, Department of Neuroscience, Rome, Italy

^g IRCCS C. Mondino National Neurological Institute, Epilepsy Centre, Pavia, Italy

^h Paracelsus Medical University, Department of Neurology, Christian Doppler Klinik, Salzburg, Austria

ⁱ School of Public Health, University of Genoa, Department of Health Sciences (DISSAL), Genoa, Italy

^j 'Sapienza' University of Rome, Human Neuroscience Department, Rome, Italy

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ABSTRACT

Wikipedia is the most commonly accessed source of health information by both healthcare professionals and the lay public worldwide. We aimed to evaluate information-seeking behavior of Internet users searching the Italian Wikipedia for articles related to epilepsy and its treatment.

Using Pageviews Analysis, we assessed the total and mean monthly views of articles from the Italian Wikipedia devoted to epilepsy, epileptic syndromes, seizure type, and antiepileptic drugs (AEDs) from January 1, 2015 to October 31, 2017. We compared the views of the article on epilepsy with those of articles focusing on Alzheimer's disease, migraine, multiple sclerosis, syncope, and stroke and adjusted all results for crude disease prevalence.

With the only exception of the article on multiple sclerosis, the adjusted views for the Italian Wikipedia article on epilepsy were higher than those for the other neurological disorders. The most viewed articles on seizure type were devoted to tonic-clonic seizure, typical absence seizure, tonic convulsive seizures, and clonic convulsive seizures. The most frequently accessed articles on epilepsy syndromes were about temporal lobe epilepsy and Lennox–Gastaut syndrome. The most frequently viewed articles on AEDs were devoted to valproic acid, carbamazepine, and levetiracetam.

Wikipedia searches seem to mirror patients' fears and worries about epilepsy more than its actual epidemiology. The ultimate reasons for searching online remain unknown. Epileptologists and epilepsy scientific societies should make greater efforts to work jointly with Wikipedia to convey more accurate and up-to-date information about epilepsy.

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1. Introduction

Every day, millions of people use the Internet to search for health-related information, and analysis of the ever increasing searches and traffic data (the so-called "big data") can allow the exploration and understanding of online attitudes. Big data analysis has resulted in the new field of "infodemiology", defined as "the science of distribution and determinants of information in an electronic medium, specifically the Internet, or in a population, with the ultimate aim to inform public health and public policy" [1].

The free online encyclopedia Wikipedia is "the largest and most popular general reference work on the Internet" and the fifth most popular website [2]. The Italian language edition of Wikipedia (Italian Wikipedia) created in 2001 represents the 8th largest version of Wikipedia based on the number of articles (after the English, Swedish, German, Dutch, French, Cebuano, and Russian editions) as of November 2017 [2].

The aim of this study was to evaluate information-seeking behavior of Internet users searching the Italian Wikipedia for articles related to epilepsy and its treatment. In particular, we aimed (1) to identify the most viewed Italian Wikipedia articles on epilepsy and related treatment and the prevailing modalities of Internet access, (2) to evaluate whether the number of views of the Italian Wikipedia article on epilepsy reflects the actual prevalence of the disease, and (3) to identify

* Corresponding author at: Department of Neurosciences, Biomedicine and Movement Sciences, University of Verona, Piazzale L.A. Scuro, 10-37134 Verona, Italy.
E-mail address: dr.francescobrigo@gmail.com (F. Brigo).

any news temporally related to the peak in views for the Italian Wikipedia article on epilepsy.

2. Methods

Using Pageviews Analysis (accessed through http://tools.wmflabs.org/pageviews/#project=it.wikipedia.org&pages=Pagina_principale), we assessed the total and mean monthly number of page views of the Italian Wikipedia articles devoted to epilepsy, epileptic syndromes, seizure types, and antiepileptic drugs (AEDs) (Table 1) from January 1, 2015 to October 31, 2017.

More novel AEDs (e.g., eslicarbazepine acetate, perampanel) could not be assessed as no articles concerning them were available on the Italian Wikipedia at the time of the searches.

For each article, we calculated the total and mean monthly number of page views according to the modality of Internet access: web mobile (browser-based Internet services accessed from handheld mobile devices), desktop (access to the Internet from the desktop), or mobile (access to the Internet through Wikipedia's app downloaded on handheld mobile devices).

The normalized information-seeking (NIS) was estimated for any of the Wikipedia articles on the following neurological disorders: epilepsy, multiple sclerosis, syncope, stroke, migraine, and Alzheimer's disease. The NIS was obtained by dividing the mean monthly views of the Italian Wikipedia article for any prespecified disease by the corresponding crude prevalence in Italy (expressed as per hundred thousands). Prevalence was preferred over incidence as an epidemiological measure to estimate NIS since epilepsy is a chronic condition and people with epilepsy, their relatives, and physicians are likely to seek online information over the entire disease course and not only at the time of the diagnosis. The NIS allowed the normalization of the number of page views according to disease epidemiology, and it was developed as a straightforward tool to evaluate whether online information-seeking for a certain clinical condition reflects its actual prevalence in the general

population and identify disparities between health-related informative need and disease burden. The most recent data on the crude prevalence of any of the selected neurological disorders in Italy were retrieved through an extensive search of the literature [3–7]. Lifetime cumulative incidence in a Dutch population was used for syncope [8] since no epidemiological study was available in Italy.

The NIS of the Italian Wikipedia article on epilepsy was then divided with the NIS obtained for any of the articles on selected neurological disorders. In this way, we obtained a relative measure indicating how many times the total number of views for the Italian Wikipedia article on epilepsy exceeds those for the other neurological diseases, normalized for their crude prevalence. In other terms, this index synthesized the informative needs of Wikipedia users for epilepsy compared to the other neurological disorders after adjustment for actual disease epidemiology.

Finally, we identified the peak in views for the Wikipedia article on "epilessia" (epilepsy) using Pageviews Analysis and searched for any news on epilepsy temporally related to the peak in views using Google (Filter: News; <https://www.google.it/>).

3. Results

The most viewed Italian Wikipedia articles on seizure types were those devoted to tonic-clonic seizure (total views: 51,654; mean monthly views: 1845), typical absence seizure (total views: 45,985; mean monthly views: 1642), and tonic convulsive seizures and clonic convulsive seizures (total views: 22,135; mean monthly views: 791) (Supplementary material). The two most frequently consulted articles on epilepsy syndromes were those on temporal lobe epilepsy (total views: 45,414; mean monthly views: 1622) and Lennox-Gastaut syndrome (total views: 38,125; mean monthly views: 1362) (Supplementary material).

The most frequently accessed Italian Wikipedia articles on AEDs were those on valproic acid (total views: 162,895; mean monthly views: 5.818), followed by carbamazepine (total views: 144,730; mean monthly views: 5.169) and levetiracetam (total views: 84,030; mean monthly views: 3.001). The least viewed articles were those of lacosamide (total views: 9,903; mean monthly views: 354), zonisamide (total views: 8,352; mean monthly views: 298), and brivaracetam (total views: 2,053; mean monthly views: 73) (Supplementary material).

After normalization for the crude prevalence, the most viewed Internet Wikipedia articles concerned multiple sclerosis (NIS: 188.7), followed by epilepsy (27.8) and stroke (16.7) (Table 2).

The number of adjusted views of the Italian Wikipedia article on epilepsy was higher than that of the articles for all other neurological disorders except that of multiple sclerosis. The normalized views for the "epilepsy" article were 70, 2, 21, and 2 times higher than those of the articles on syncope, Alzheimer's disease, migraine, and stroke, respectively. Conversely, the adjusted views of the article on multiple sclerosis were 7 times higher than those of the article on epilepsy.

For any article (epilepsy and the other neurological disorders, epileptic syndromes, seizure types, and AEDs), the prevailing way of accessing the Internet to consult Wikipedia was through browser-based Internet services accessed from handheld mobile devices (web mobile), followed by access to the Internet from the desktop (desktop), and through Wikipedia's app downloaded on handheld mobile devices (mobile).

The peak in views for the Italian Wikipedia article on epilepsy (6747 views) occurred on October 5, 2016 (Fig. 1), and it was strictly related from a temporal point of view to the news headline publishing the results of a report by a panel of experts about a second investigation into the case of Stefano Cucchi, a young man who died under police custody in 2009 one week after being arrested for dealing illegal drugs [9]. A report by a panel of experts said that Stefano Cucchi suffered a "sudden, unexpected death due to epilepsy in a man who had had epilepsy for many years and was being treated with anti-epilepsy drugs" [9].

Table 1
Italian Wikipedia articles on epilepsy and epileptic syndromes, seizure types, and AEDs evaluated in this study.

Italian Wikipedia articles considered in the present study
<i>Articles on epilepsy and epileptic syndromes</i>
'epilessia' (epilepsy)
"epilessia autosomica dominante notturna del lobo frontale" (autosomal dominant nocturnal frontal lobe epilepsy)
"epilessia del lobo temporale" (temporal lobe epilepsy)
"epilessia mioclonica giovanile" (juvenile myoclonic epilepsy)
"epilessia mioclonica progressiva" (progressive myoclonic epilepsy)
"epilessia tipo assenza giovanile" (juvenile absence epilepsy)
"epilessia tipo assenza infantile" (childhood absence epilepsy)
'epilessia'
"sindrome di Janz" (Janz syndrome)
"sindrome di Lennox-Gastaut" (Lennox-Gastaut syndrome)
<i>Articles on seizure types</i>
"assenza tipica" (typical absence seizure)
"assenza atipica" (atypical absence seizure)
"crisi atoniche" (atonic seizures)
"crisi convulsive toniche e crisi convulsive cloniche" (tonic convulsive seizures and clonic convulsive seizures)
"crisi tonico-clonica" (tonic-clonic seizure)
"stato epilettico" (status epilepticus)
<i>Articles on antiepileptic drugs</i>
"acido valproico" (valproic acid)
"brivaracetam"
"carbamazepina" (carbamazepine)
"fenitoina" (phenytoin)
"fenobarbital" (phenobarbital)
"lacosamide"
"lamotrigina" (lamotrigine)
"levetiracetam"
"topiramato" (topiramate)
"zonisamide"

Table 2

Mean monthly views of the Italian Wikipedia articles on the neurological diseases, crude disease prevalence values in Italy, and normalized information-seeking (mean monthly views of the Italian Wikipedia article adjusted for the corresponding crude prevalence of the disease).

Neurological disease	Mean monthly views of the corresponding Italian Wikipedia article ^a	Crude disease prevalence in Italy (expressed as per hundred thousands)	Normalized information-seeking (NIS)
Epilepsy	21,986	790 [3]	27.8
Alzheimer's disease	24,908	2090 [6]	11.9
Migraine	15,121	11,600 [4]	1.3
Multiple sclerosis	33,214	176 [7]	188.7
Syncope	14,345	35,000 [8] ^b	0.4
Stroke	24,492	1470 [5]	16.7

^a From January 1, 2015 to October 31, 2017.

^b Lifetime cumulative incidence in a Dutch population.

The results of this report were published on October 4, 2016, the day before the peak in views for the Italian Wikipedia article on epilepsy. No other news published in the preceding days was likely to drive online searches toward the Wikipedia article about epilepsy.

4. Discussion

Our study reveals that the views of the Italian Wikipedia articles on epilepsy and other neurological conditions do not strictly reflect the corresponding disease epidemiology after adjustment for the actual prevalence: Wikipedia users tend to search online information for epilepsy more frequently than for the other disorders of the nervous system. One notable exception is represented by multiple sclerosis, whose Internet Wikipedia article views were approximately 7-fold that of the article on epilepsy. This attitude might be explained by the fact that multiple sclerosis predominantly affects young patients, who notably have higher rates of Internet usage compared to children and the elderly [10,11], while epilepsy is more widely distributed across all ages. Wikipedia users may search for online information on epilepsy more frequently because they consider it more severe than other neurological conditions (e.g., migraine or syncope), even if less common. This perceived seriousness might also explain the higher views for the Wikipedia articles addressing tonic-clonic seizure, tonic convulsive seizures, and clonic convulsive seizures (total views: 73,789; mean monthly views: 2636).

Accordingly, the current study suggests that Wikipedia searches mirror patients' fears and worries more than the actual epidemiology of epilepsy and epileptic seizures [12]. In this respect, the likelihood that the overall volume of online searches may be greatly influenced by patients' emotions and individual perceptions of disease severity has just been shown for different neurological conditions, including movement disorders [13] and multiple sclerosis [14].

Similarly to what occurs in online searches for many non-neurological diseases [15–18], web searches of information for disorders affecting the nervous system like multiple sclerosis, dementia, stroke, or epilepsy can be driven by the release of news about celebrities suffering from these disorders (so-called “Robin Williams' phenomenon” [19]) and “breaking news” or mass media events referring to neurological diseases [13,20,21].

The highest peak in views for the Italian Wikipedia article on epilepsy immediately followed the news on Stefano Cucchi's “unexpected death due to epilepsy”. Unlike previous studies, the peak was not driven by news involving celebrities, as previously reported [13,14,18,20–22], but was related to crime news and judicial reporting.

In Italy, the case of Stefano Cucchi had a huge mediatic impact on the broad public, not the least because his family claimed that he had died following injuries received during his detention [23]. The strict temporal correlation between the news on Stefano Cucchi's epilepsy-related death and the peak in views for the Italian Wikipedia article on epilepsy confirms that emotions play a great role in guiding web searches to

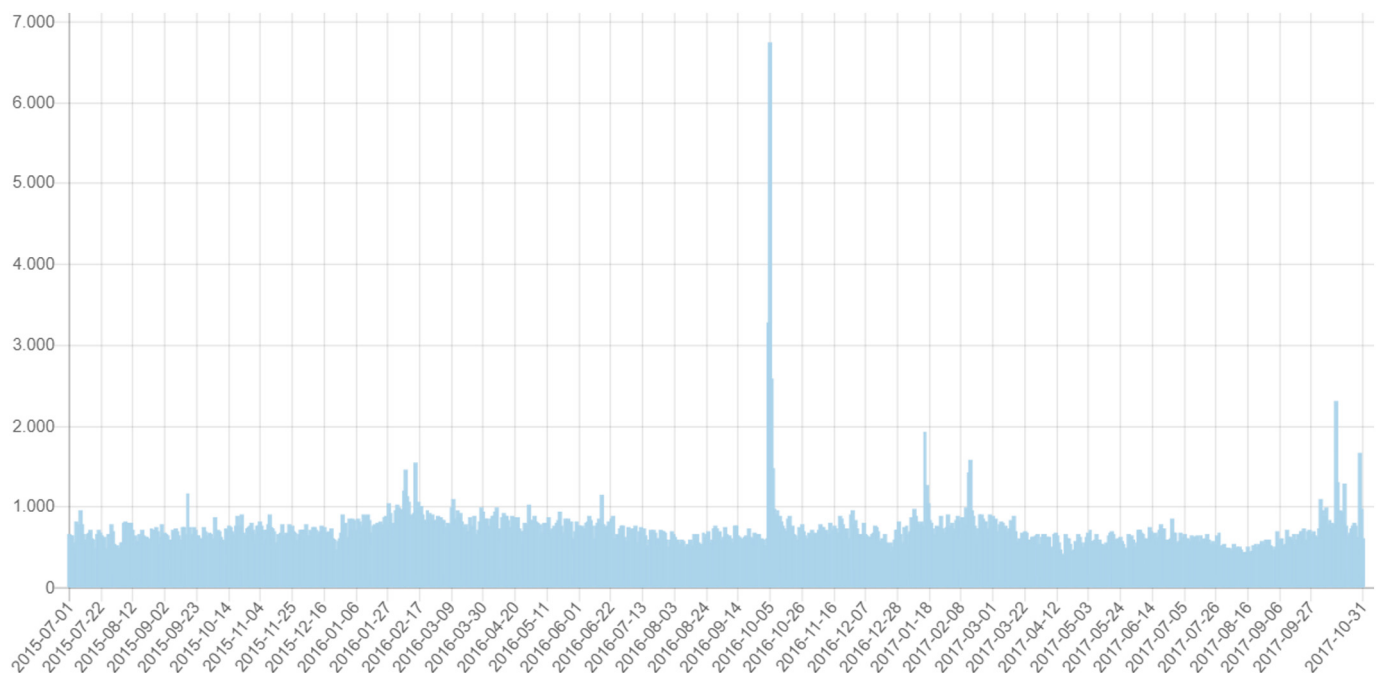


Fig. 1. Total daily views for the Italian Wikipedia article on epilepsy from July 1, 2015 to October 31, 2017. The peak in views was recorded on October 5, 2016.

obtain health information [12,14,22]. The influence of this case in driving the page views is further underlined by the highest peak in views for the Wikipedia article on tonic-clonic seizure observed on January 17, 2017 (474 views), the same day when a new expert report was published, saying that “there is no evidence that epilepsy has caused the death [of Stefano Cucchi]” [24].

The overall use of AEDs could be one of the factors determining the number of views of the corresponding Wikipedia articles. This might explain, for instance, why the article on brivaracetam, which is not yet approved in Italy, had the lowest number of views. Other variables, which may influence the amount of views of articles on antiepileptic treatments, include the use of the same pharmacological agent for conditions other than epilepsy (this would reduce the specificity of the results on information-seeking) or the tolerability profile of the drug itself (some users may search online information after experiencing adverse effects). With regard to this last aspect, the high number of views for the article on valproic acid might be related to its increased risk of teratogenicity and to the recent warnings against its use in women of childbearing age [25,26].

The findings coming from infodemiological studies should be interpreted with caution, taking into account that variables other than epidemiology may influence the search volume and being aware that the ultimate reasons underlying the online searches cannot be fully understood. Despite these obvious limits, the current study provides useful insights to inform public health and public policy with the final aim of improving the overall quality, accessibility, readability, and accuracy of epilepsy-related information available online. On this ground, the International League Against Epilepsy (ILAE) has recently launched the ILAE-Wikipedia project with the objective “to convey through Wikipedia the most authoritative and up-to-date information about epilepsy, working jointly with ILAE journals” [27]. In conclusion, infodemiology may provide useful findings to inform public health and public policy. Wikipedia is among the most common and frequently accessed online sources of data about epilepsy and its treatment: epileptologists and epilepsy scientific societies should make greater efforts to work jointly with Wikipedia to convey accurate and up-to-date information.

Conflicts of interest

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The other coauthors have no conflicts of interest.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.yebeh.2018.01.037>.

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