#Crohn's: Historical Cohort of Twitter Activity

Marcio Roberto Facanali Junior, MD,* Carolina Bortolozzo Graciolli Facanali, MD,*• Natália Sousa Freitas Queiroz, MD, PhD,† Carlos Walter Sobrado Junior, MD, PhD,† Sérgio Carlos Nahas, MD, PhD,† and Adriana Vaz Safatle-Ribeiro, MD, PhD†

Background: Analysis of the Twitter activity on #Crohn's, identifying individuals with interest in Crohn's disease on Twitter.

Methods: A historic cohort study was conducted about Twitter activity evaluation of #Crohn's analyzed over a period of 9 years. For the Twitter analysis, a health-care social media analytics tool, Symplur Signals, was adopted.

Results: From 2011 until 2019, 627,000 tweets of #Crohn's were detected, with 276,380 retweets by 109,937 users; of these users, 32.4% were patient advocates and 12.6% were doctors. There was a pattern of annual peak activity of the #Crohn's, mainly in May and December, and less activity, usually in July. Of all tweets, 52.5% were categorized as positive and 47.5% as negative.

Conclusions: Social media, especially Twitter, represents an important information tool, but it is still underutilized by gastroenterologists. This study suggests a significant interference of international awareness campaigns about inflammatory bowel disease in the activity of #Crohn's on Twitter, denoting an increase in debating this topic on the platform. Discussions on the subject by health professionals are still below expectations regarding the importance of the theme.

Lay Summary

Descriptive article exploring the hashtag #Crohn's on Twitter, relating its activity in a historical and chronological context.

Key Words: inflammatory bowel disease, Crohn's disease, Twitter, purple May, social media

INTRODUCTION

Crohn's disease is characterized by transmural lesions affecting any part of the gastrointestinal tract, from the mouth to the anus.¹ It is a common condition that has considerable impact on young adults and patients at all stage of life, with increasing incidence in the developing world.²

The search of updated health or medical information has undergone a major paradigm shift over the past years with the

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emergence of the Internet. In addition, social media has been raised as an important information tool for patients seeking out information regarding many chronic illnesses. Given that the peak incidence of inflammatory bowel disease (IBD) occurs between the second and third decades, the use of social media has been reported as a source of IBD-related information and education by patients with IBD in the management of their disease. For instance, Reich et al revealed that patients with IBD are increasingly using Internet and social media for its illness management, and that 62% of these patients would like to follow a social media account indicated by their gastroenterologists.³ Accordingly, Cima et al reported that 54% of patients with IBD used the Internet to collect specific information.⁴

As a consequence of the recent shift in the traditional patterns of health information seeking, there is a rapid increase in the number of online platforms delivering information from recognized health institutions. As stated by Mayo Clinic Health Care, in 2012, 1583 of 6562 hospitals in the United States had accounts on social media, such as Twitter, YouTube, and Facebook, with more than 1000 hospitals on Twitter alone.⁵ Based on United States News and World Reports (USNWR), the organization who has been publishing annual rankings of hospitals since 1990, the acquisition of Twitter followers between 2014 and 2016 was associated with improved divisional raking.⁶ Further, tweeted articles had a trend to significantly increase the citation rates in journals than untweeted articles.⁷

A study conducted by Davis et al in 2013 assessed the attitudes of North American gastroenterologists toward social

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^{*}Department of Gastroenterology of Hospital das Clínicas of University of São Paulo Medical School, São Paulo, São Paulo, Brazil; †Department of Gastroenterology of Hospital das Clínicas of São Paulo, São Paulo, São Paulo, Brazil

Address correspondence to: Carolina Bortolozzo Graciolli Facanali, MD, Avenida Doutor Arnaldo, 455, Bairro Cerqueira Cesar, CEP: 01246-903, São Paulo, SP, Brazil (cbgraciolli@hotmail.com).

media in health care. At that time, the majority of the respondents disclosed that they were not interested in social-media-based education, although Facebook and Twitter were identified as the most popular social media used.⁸ Despite that, recent data revealed Twitter as the most frequently used smartphone applications by some medical specialties such as coloproctology, plastic surgery, vascular surgery, and urology.^{9–13}

As Twitter has become a major hub for health-related discussions lately, the development of "hashtag ontologies" has evolved as an interesting tool to allow organized searches on specific medical topics. Accordingly, a gastroenterology hashtag ontology list was recently devised, organized by subspecialties.¹⁴ The aim of this study was to provide a longitudinal comprehensive analysis of the Twitter activity on #Crohn's, identifying individuals with interest in Crohn's disease on Twitter through this hashtag. Other hashtags such as #Crohn'sDisease, #IBD, and #ulcerativecolitis have been excluded.

METHODS

A historic cohort study was adopted to help understanding the Twitter activity evaluation of #Crohn's, analyzed over a period of 9 years, from its creation in 2011 to 2019.

The search included individuals and institutions that have an active Twitter account and that actively interact with #Crohn's during the period of this study.

Symplur Company has created the online Healthcare Hashtag Project (Symplur, 2014), and with the Symplur Signals (www.symplur.com/signals), a fee-based research analytics tool, hashtags can be registered, allowing the extraction and analysis of the data, including accounts of physicians, patients, and other stakeholders with access to health-care social media data. The number of tweets and "retweets" was analyzed. Retweets are similar to direct mentions of other user's tweets. Therefore, it is a method of digitally spreading the content of another user, increasing its audience. Data associated with the number of "impressions," number of views, number of all tweets, and the number of users who had used the hashtag #Crohns were also collected.

A "Sentiment Analysis" was carried out by Symplur platform through the use of artificial intelligence to classify declarations as positive or negative. "Sentiment Analysis" is powered by a natural language-processing algorithm optimized for health care and is proprietary to Symplur. This algorithm determines polarity regarding health-care issues by means of grammar analysis, sentence structure, parts of speech, punctuation, emoticons, slang terms, and shortened terms that are common in social media. Each sentiment score is also weighed accordingly based on the tweet author's influence in health care. Data on demographics for #Crohn's twitter posts were also documented.

Ethical approval was not indicated or sought for this study. However, the consideration to ethical principles was incorporated, since all participants included in the analysis agreed to Twitter's terms and conditions.

RESULTS

Five trending hashtags were identified according to the gastroenterology ontology list, comprising 2,633,215 tweets from 2011 to 2019: #GERD, #PancreaticCancer, #NAFLD, #ColonCancer, #IBD, and #Crohns.

#Crohn's was responsible for 627,000 tweets and 276,380 retweets by 109,937 users in this period (Figs. 1, 2).

As a marker of audience and impact, #Crohn's tweets received 2,839,198,478 impressions over the study period, with 2013 being responsible for 50.31% of them.

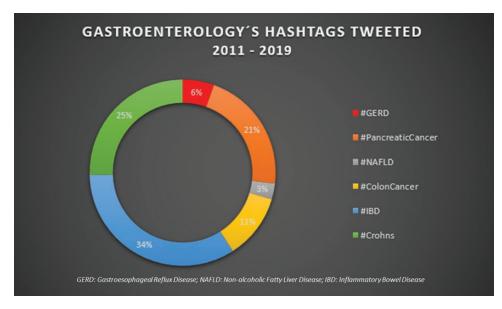


FIGURE 1. Hashtags trends over 9 years.

Influencers identified by the Symplur for #Crohn's were patient advocates in 32.4% and physicians in 12.6% of the cases (Fig. 3). The results of the distribution in several countries around the world are demonstrated in Figure 4.

When the analysis of #Crohn's was performed by year, it was observed as a bimodal design with peaks in May and December, which becomes more evident after 2016, the year with the largest amount of tweets of all analyzed periods. The peak of the activity was seen in January of 2016 (Fig. 5).

The network analysis of the tweets on #Crohns is provided in Figure 6, which gives an overview of users that are central to the Twitter discussion and the interaction between them. Of all tweets, 52.5% were categorized as positive statements and 47.5% were categorized as negative statements.

DISCUSSION

Social media has emerged as an important tool for online health information seeking by patients and medical professionals in different areas and specialties, with Twitter being one of the most popular platforms.

In accordance with some previous reports, this study has identified that nonphysicians users used much more #Crohn's than physicians, suggesting that they use more social media to seek out health information.^{3,4,8} Gastroenterologists, when compared with other users, have low #Crohn's activity. However,

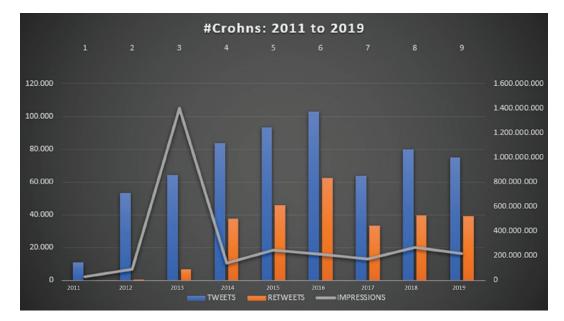


FIGURE 2. #Crohn's over 9 years.

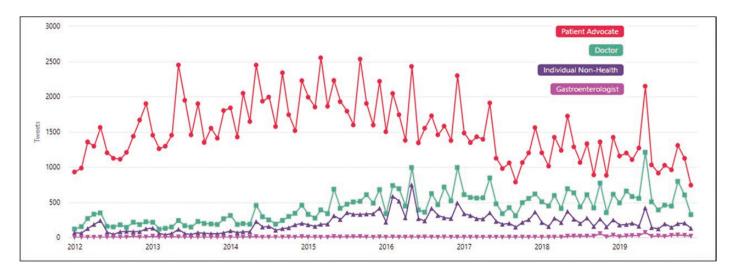


FIGURE 3. #Crohn's tweet activity.

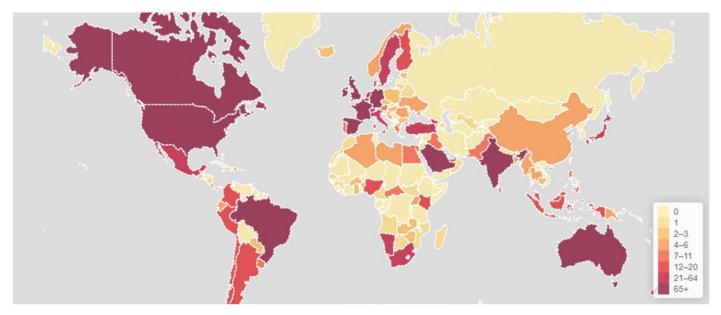


FIGURE 4. #Crohn's user locations.

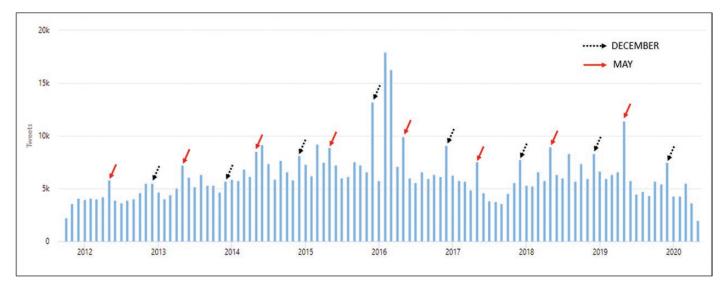


FIGURE 5. #Crohn's monthly activity.

a slight increase in physician's activity has been observed in the past 2 years. There was also a greater concentration of all users who used #Crohn's in countries where the prevalence of Crohn's disease is higher.²

When analyzing the activity of the hashtag #Crohn's, a trend for greater activity was observed in the months of May and December, which became more evident after 2016. On the other hand, lower rates of activity were observed in July. This fact may be associated with annual campaigns that raise awareness about IBD since 2010, when, during Digestive Disease Week (DDW) in New Orleans, Louisiana, USA, the World Organization for Gastroenterology (WGO) and the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) decided to choose May 19 as the International IBD Day. This date was created with the purpose of bringing people together from all over the world for fighting against Crohn's disease and ulcerative colitis. After that, this month became known as purple May.¹⁵

Another historical fact that may be related to #Crohn's activity peaks in December is the US Senate Resolution 199, originally dated at the week of December 1 to December 7, in 2011, when support for the Week's goals and ideals was performed through Crohn's and Colitis Awareness Campaign, encouraging media organizations to participate in the week, thereby helping to educate the general public about IBD. Since

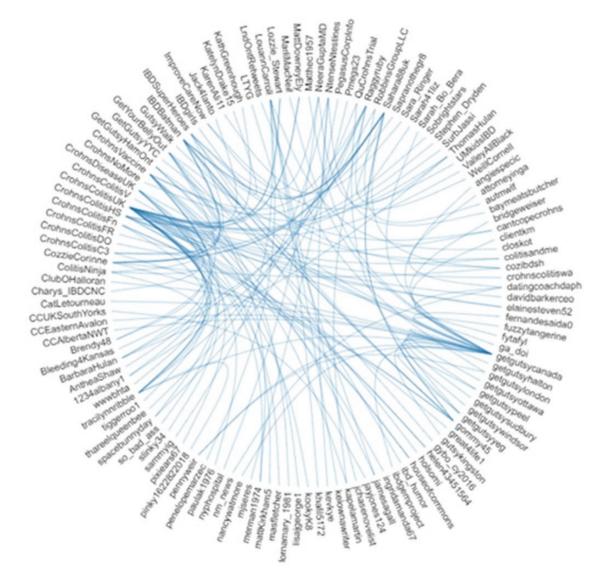


FIGURE 6. #Crohn's conversation identifier.

then, Crohn's and Colitis Awareness Week continues to be celebrated annually from December 1 to 7.

India, Saudi Arabia, Brazil, and South Africa, considered emerging countries, had number of tweets similar to those of developed countries, such as North America and European countries. This finding may mirror recent advances in technology in the developing world, increasing possibilities for the use of social media with the purpose of information seeking.

Although very speculative, an IBD-related debate held in February 2016 in the smaller Westminster Hall debating chamber by the UK health minister might be the cause of #Crohn's peak activity on Twitter in 2016, representing the largest historical index ever recorded.

It is important to emphasize that patients with IBD comprise a vulnerable population, often requiring frequent outpatient medical follow-up, where they usually address numerous questions regarding their disease. When institutions deliver accurate information provided by professionals experienced in IBD management through a communication network, patients can feel more confident and welcome. Moreover, the use of specific Twitter hashtags, for a target population, expands a network that transcends borders and languages, and the health service can be recognized as an influencer who is capable of generating powerful social interactions. In the near future, it is very likely that the spread of accurate virtual content can even minimize face-to-face consultations or, otherwise, act as part of integrative care.

Even though the used hashtag (#Crohn's) was previously defined in a standardized reporting ontology system, it is not certain whether it does reflect with accuracy all the information and interactions of users about IBD and especially Crohn's disease. In addition, content verification is limited due to the use of special algorithms that may not be able to detect linguistic peculiarities.

CONCLUSIONS

Social media, especially Twitter, represents an important information tool, but it is still underutilized by gastroenterologists. This study suggests that the activity of #Crohn's on Twitter suffers significant interference of international IBD awareness campaigns, reinforcing the role of this platform in providing rapid and broad transit of impactful information.

Whether social media would positively impact medical education in the field of gastroenterology is still uncertain and needs to be further assessed.

DATA AVAILABILITY

Data not publicly available.

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