

Online social networks and inflammatory bowel disease

Enrolling patients for epidemiologic studies represents a challenge for researchers. Those who use traditional approaches, including in-person interviews and telephone or mail surveys, obtain increasingly lower participations. In the study by Martín-Fernández et al. (1), the authors obtained 44 responses via mail and forums, and then 376 responses in just five days via Facebook.

Online social networks (OSN) provide a unique opportunity to obtain epidemiologic data with resource savings and presumably collecting higher-quality information. However, disadvantages include loss of anonymity, selection and sampling biases, social acceptance bias, behavior changes, and lack of representativity.

The OSN concept is defined as social structures composed of a group of people who share a common interest, relationship or activity via the Internet, where social encounters take place and preferences in information use are shown. This concept has become a common language expression involving designations such as Facebook or Twitter (2).

There is an ever increasing number of Internet and OSN users in our setting. In the "Survey on information and communication technology equipment and use" carried out in Spain by the Spanish Instituto Nacional de Estadística in 2014, approximately 98% of subjects between 16 and 24 years of age, and 91% of those between 25 and 44 years of age, were Internet users. In the US, 93% of adolescents and young adults use the Internet, and 73% participate in OSN (3). Furthermore, in 2016, according to the agency We Are Social, 77% of the Spanish population used the Internet, and 48% had profiles in OSN. Facebook is most widely used, involving 44% of the population. In Australia, 87% of individuals from 18 to 24 years of age regularly use Facebook (4). In Europe, 70% of adolescents between 14 and 17 years of age use OSN, and 40% do so for two or more hours a day (5).

It seems, therefore, that OSN may be a useful, cost-effective source of participants for epidemiologic studies in the young adult population, as shown by a meta-analysis reported in 2014 (6). Also, in that same year, the University of Queensland's School of Public Health (7) gathered a cohort of 17,069 women born from 1989 to 1995 by using OSN and other conventional approaches. Facebook was the most useful enrollment tool, providing 70% of said cohort (a total of 11,799 women). The data obtained were compared to the data included in the 2011 Australian Census and the 2011-2012 Australian Health Survey, and no significant differences were found. The authors concluded that the sample collected via OSN was wide, heterogeneous and representative of the population.

That is, if we are considering an epidemiologic study, our first choice should be the use of Facebook as a tool for enrolling subjects. Furthermore, should our study focus on patients with inflammatory bowel disease (IBD), bearing in mind that this diagnosis is most common within the range from 15 to 35 years of age, the incorporation of OSN to epidemiologic research seems crucial.

These behavioral changes also impact the way information is sought. In the US, 61% of adults search the Internet for health-related information, and 39% use OSN to this purpose (8). In the United Kingdom, Facebook is the fourth most commonly used source of health-related information (9). In the study by Martín-Fernández et al. (1), almost 30% of patients considered that the Internet was the most useful source of information to solve health concerns, and 60% used social network pages to this purpose; however, most participants reported that information collected from the web did not condition their final decision making.

The reasons that lead patients and professionals to use these technologies include information seeking, need for social support, improved care quality, exploring self-care and self-education, and enhancing doctor-patient relationship (10-13). According to a Dutch study from 2012 (14), patients used Twitter primarily to obtain knowledge and exchange information, and Facebook to obtain social support, express emotion and improve knowledge. Providers used LinkedIn and Twitter mainly to communicate with peers and to promote themselves or their institution. The response rate obtained from professionals in this study was merely 12%, which shows that OSN and their health care applications arouse no interest for most practitioners.

Studies are available showing that the so-called e-Health (15) technologies, as applied to the management of patients with IBD, increase remission time, improve adherence and quality of life, reduce costs and visits to the Emergency Room, facilitate remote management, and allow self-care (16,17). OSN represent highly useful communication (18), education, empowerment, and behavior modulation (19).

However, virtually no studies have assessed the behavior patterns of patients with IBD, the groups and communities they make up as well as their relationships, their opinion leaders, the keywords they use, or the information and opinions they share in OSN.

There is a study that was presented in Paris in 2015, at the International Conference on Advances in Social Network Analysis and Mining (ASONAM), by Rocchetti (20), in which Twitter and Facebook were used to analyze the information shared by patients with Crohn's disease. The study revealed which topics are most popular and the behavior patterns involved as well as their relevance. It also used sentiment analysis to collect opinions on the various therapies without ever contacting patients directly. The study used the keyword or hashtag "Crohn" and reviewed 49,658 posts in 6,746 Facebook accounts from October 2011 to October 2013, as well as 26,737 posts in 12,071 Twitter accounts from April 2013 to October 2013. Messages posted in Twitter were more representative and useful to understand behavior patterns. The top ten active users in Facebook and Twitter posted 8% and 5% of messages, respectively, and only 261 Facebook users and 201 Twitter users posted at least ten messages. In all, 60% of messages posted in Facebook had to do with symptoms and treatment, 25% with causes, and 10% with medication-related adverse events; 90% of tweets include symptom-related terms. Facebook users usually post personal experiences, and Twitter users post about disease-related information campaigns and scientific literature news. Also common are tweets on the relationship between diet and symptom development or remission. In analyzing Facebook posts the study found that patients with Crohn's disease discuss the causes of their conditions, particularly about bacteria, genetics and vitamin deficiencies. Finally, the sentiment analysis established that infliximab, adalimumab and azathioprine were the drugs receiving most positive opinions and arousing greatest interest, most particularly infliximab, which the study found to be the drug with the highest impact in social networks. The author completed this sentiment analysis in a recent publication reported in 2017.

Taking a further step forward, data mining, as applied to OSN, notably to Twitter, has been the focus of multiple recent studies, and software programs have been developed for data collection and evaluation, trend assessment, and sentiment analysis. This allows the collection of data on public health, the identification of influence epidemics, the detection of drug-related adverse effects, the study of behavior patterns (21), the identification of depressive symptoms (22-24), the comparison of patients with schizophrenia with a control group, or the development of automated models to detect new cases of schizophrenia (25).

Finally, in 2011 the Royal Dutch Medical Association urged to "take advantage of the potential entailed by social networks" in order to educate and involve professionals in their use. Maroto-Martín C et al., in an excellent review (26), recommend that we should be more sensitive to information needs, improve patient education, and endorse the use of Facebook and Twitter to get to know what patients need, and to provide them with safe and accurate information, while also aptly advising against the use of personal accounts. Furthermore, Mayol J and Dziakova J, in an editorial (27), discuss how OSN are transforming communication for modern surgical research, facilitating access to information, and allowing the development of novel platforms to enhance communication and cooperation amongst researchers, clinicians, patients, scientific societies, and journals. Therefore, gastroenterologists, particularly those involved in caring for IBD, should take advantage of the potential and opportunities OSN offer in order to:

- Enroll subjects in epidemiologic studies.
- Facilitate safe and accurate information.
- Promote remote management and self-care.
- Improve adherence, quality of life, and disease outcomes.
- Complement the results of clinical trials for newer therapies or interventions using sentiment analysis.
- Develop collaborative networks to facilitate information sharing and the development of multicenter studies.
- Enhance the visibility and spreading of research work.

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