

# Inside Chronic Autoimmune Disease Communities: A Social Networks Perspective to Crohn's Patient Behavior and Medical Information

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**Abstract**— Anonymity, speed and big data are all ingredients at the basis of an intense online medical information prosumerism supported by search-engines, websites, forums and social networks. Fostering reliable medical ecosystems requires an exploitation of such data, controlling quality and delineating user behaviors. This strongly emerges with chronic patients: they are expected to devote a long use of the Internet on the same health topics; nonetheless a limited amount of research has investigated their online resources and behavior. We uncover the role of online social networks for a growing community of chronic patients: Crohn's disease patients. Our contribution is twofold: (a) we characterize the data exchanged by Crohn's patients, (b) while analyzing how they deal with given topics of medical interest. In particular, of great medical relevance is the result that *Infliximab* is the treatment that mostly influences the Crohn's patient community sentiments. We are confident our analysis of the health heritage exchanged online can help improve Crohn's patients' experience, exceeding the traditional practices that typically concentrate on individuals rather than on communities.

**Keywords**— Health; Social Networks; Chronic autoimmune diseases; Crohn's Disease; Well-being

## I. INTRODUCTION

A very common practice today has become that of searching for medical information online. Many people search for symptoms, medical advice and remedies, often because they are experiencing some sort of injury or health problems (one-third of adult American citizens, consider the Internet a diagnostic tool [1]). This is an interesting phenomenon, as the online sharing of information, stimulated by a perceived online anonymity (effective anonymity is a rising problem, as reported in [2]), may boost frankness and sincerity about personal troubles and experiences. This is true both for sporadic and for chronic patients: the former tend to search for reassuring information concerning their symptoms, the latter for any news concerning more efficient treatments and solutions [3]. Chronic patients, in particular, often spend vast portions of their lifetime optimizing their treatment and lifestyle, in order to achieve the highest possible quality of life. This specific class of patients, hence, acquires in depth knowhow and develops a high degree of self-consciousness of how a diseases should be dealt with, when compared to

occasional patients. When such patients share their experience online, they can potentially provide extremely valuable insights to both new people that have been diagnosed with the same problem and medical researchers [4]: the former can learn how certain situations have been handled before, while the latter can rapidly assess given treatments' side effects, for example.

With the advent of online tools, in fact, the scenario in front of caregivers has been radically changed since chronic patients are set in front of many more stimuli than those that have been for long budgeted by healthcare professionals or traditional support groups. Updating a metaphorical portrait that was provided in [5], where chronic disease patients were represented as pilots of small airplanes that rarely touched the ground and health care professionals as copilots that could be on the planes for only a few hours every year, today a myriad of copilots are available online. The problem with these new copilots that can appear and disappear onboard is whether they can help keeping the plane on the right route. In fact, despite the wide acceptance that online tools have received from the caregiver and patient communities, it is well understood that the exchange of information online may suffer from various kinds of fallacies, including the presence of incorrect, inaccurate, incomplete, improperly emphasized, ambiguous or disputable medical advice [6]. Nevertheless, accessing other patients' experiences can positively support and boost confidence, confirm treatment choices, provide new alternatives when facing troubling decisions (e.g., related to medications, dietary habits, etc.) and help alleviate loneliness while maintaining relations with others [7]. It is hence key assessing what type of resources are available online, for those who search given topics for the first time and for a deeper understanding of the behavior of given patient communities.

We here extend past studies along multiple directions [8]. Compared to previous work, we first investigate the role that two different popular online social networking tools, Twitter and Facebook, today play for a particular class of chronic disease patients. In both of these Online Social Networks (OSNs), we characterize the information that is exchanged online, revealing which are the topics of medical interest that emerge most above others. This included individuating how many users post information,

how active they are, as well as how popular given arguments are. In our study we also resort to sentiment analysis techniques to capture the prevailing mood that is expressed online by the community when touching upon given arguments. We concentrated such efforts on a particular class of chronic patients, Crohn's Disease (CD) ones. CD is a *type of Inflammatory Bowel Disease (IBD) that may affect any part of the gastrointestinal tract from mouth to anus, causing a wide variety of symptoms* [9]. To this date, Crohn's is one of those chronic diseases whose symptoms can be treated and alleviated, but whose cure has yet to be found. Infected people, hence, spend a very long time combating their illness symptoms (and potentially sharing information), as this disease is fatal only in rare cases. In addition, the incidence of CD is rapidly increasing, especially in western countries. A very recent study estimated the incidence of CD was of 12.7 and 20.2 per 100,000 person-years in Europe and North America, respectively [10]. Such increase is matched by a corresponding positive gradient of interest that can be observed online: the average number of monthly searches performed on Google for the keyword *Crohn's disease* over the last two years (Aug. 2012 – Jul. 2014) escalated from a volume of 300.000 searches to almost 1.000.000. Legitimately, we may conjecture that a share of those people who search for such topic online will also end up reading OSN exchanges, and in some cases also provide their own contributions.

This work adds on to those areas of human-computer research concerned with online health and to those of health care that are related with how web 2.0 technologies could be put to good use to further support and integrate chronic illness management. In particular, our contribution is twofold, as on one side it provides an understanding of what resources are available online concerning CD, while on the other it assesses how online commenters feel concerning given arguments. Indeed, we sampled the OSN bodies of CD data, individuating the most extensively covered topics, shedding light on the contributors' mood and sentiments. Essentially, our results aim at moving a first step in the creation of new means of online communication and information sharing, where patients and healthcare professionals may effectively meet, overcoming those misunderstandings and mistrusts that often build up when living a long and stressful voyage with CD. In sum, an online-centered design of these technologies could help patients better understand their health and engage with it in a meaningful way. As an example, among others, of the practical relevance of our contribution we anticipate here the result that *Infliximab* is the treatment that mostly influences the Crohn's patient community sentiments.

This paper is organized as follows. We present the works that fall closest to ours in approach, underlining the difference and the innovative aspects. We then move on to present the methodology that has been adopted in this work and exhibiting its results, finally concluding.

## II. RELATED WORK

Chronic patients online management tools are receiving a growing interest, as witnessed by a number of recent works devoted to this area [11, 12, 13, 14]. Specifically, in [11], its authors interviewed a group of 150 Lyme disease patients with the aim of finding how online resources influenced their personal view of their illness. In their interviews, the authors observed a dichotomy would often emerge between professional caregivers' and patients' visions. This was particularly noticeable when standard medical information did not match a given patient's experience: in such situations patients would often rely more on online community resources when managing his/her illness. Although we here consider a group of patients affected by a completely different disease, our approach may be viewed as complementary to the path taken in [11]. Compared to this study, we focus our attention on what is available on OSNs, without directly contacting CD patients. Along this path, however, we have relied on the aid of a group of CD physicians that have guided us through the streams of patient posts.

A second study, instead, focused on the use of video blogs as a social support for chronic illness management [12]. Its authors analyzed the videos logs published by HIV, cancer and diabetes patients observing that the use of the video medium facilitated the creation of strong connections between vloggers and their followers/commenters. Upon such grounds, the authors suggested such type of mechanisms could be exploited to facilitate patient self-monitoring and outreach. With respect to this contribution, we do not directly touch patients-support group interactions, but our analysis includes such type of interactions every time these express feelings concerning given medical topics. For this reason we believe that the work that is presented in [12] could be further extended following our approach, in order to provide further medical insights to health care professionals.

In [13], Weitzman *et al.* analyzed the information shared on diabetes-focused SN websites in two subsequent steps. They first verified the safety, transparency, accessibility and privacy policies of such sites. They secondly assessed the quality of the shared information, finding a general alignment to clinical practice recommendations. In another relevant study, its authors assessed the quality of the communication between the members of a few Facebook diabetes communities [14]. The results of this study are: (a) the majority of posts included unsolicited sharing of diabetes management strategies, (b) just a small share provided specific answers to user requests, (c) a third provided emotional support, and, (d) a relevant percentage featured some type of promotional activity.

We here extend such work in two different ways. Firstly, we assessed two different OSNs, considering both Facebook and Twitter, which by construction provide

different expressive means and utilization patterns between their active populations. Secondly, we here did not only list which topics are discussed most along with CD, but we also pointed at apprehending behavioral information, such as the sentiment expressed by those authors that posted information online.

### III. METHODOLOGY

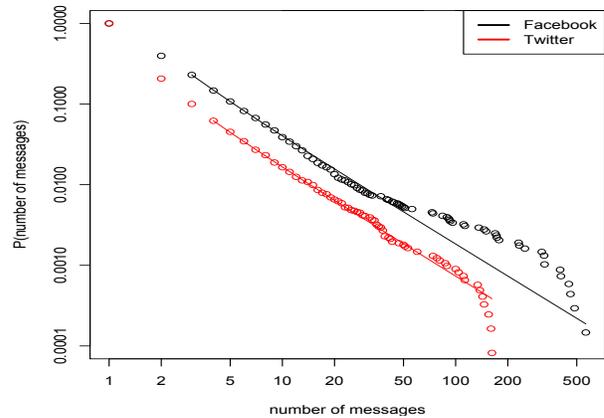
The analysis of CD posts is here accomplished searching for answers to three questions. The first question that we considered relevant for this work concerned how relevant are Twitter and Facebook for CD patients. In brief, how active is the debate about CD on these media and how does its pattern change when moving between the two? We, secondly, turned our attention at what people was saying online asking ourselves which were the most popular topics, among the most relevant for medical studies. Finally, we also analyzed the mood of who writes online by means of sentiment analysis techniques. In essence, we pointed our interest to the three following variables: 1) **CD Community Member Activity**, i.e., compute the published posts and inter-post time per member distributions; 2) **Medical Topics**, i.e., recognize the topics of greatest medical interest while investigating their use by different classes of authors; 3) **Mood vs. Pharmacological treatments**, i.e., assess the mood that emerges in correspondence with different treatments and search for any existing causality relations between given treatments and the general atmosphere that unfolds on OSN CD pages.

However, before turning our attention to the aforementioned points, we went through an initial process where we chose which portions of the mentioned OSNs would be considered for our study. We opted for those posts written in English where people discuss CD on Twitter and Facebook. Although no publications have so far assessed the CD-related activity of English-speaking users on these OSNs, expectations were high, considering approximately 1,000,000 people are affected by this disease in the United States alone [10]. We individuated the posts that discuss CD on Facebook (October 27<sup>th</sup> 2011 – October 26<sup>th</sup> 2013) and Twitter (April 30<sup>th</sup> 2013 – October 26<sup>th</sup> 2013) adopting two different approaches. For Twitter, we looked at all those posts that included the #crohn hash tag. For Facebook, instead, we sought all those messages posted on public pages that discussed CD: such search returned 53 pages, whose posts have all been utilized in our analysis. Summing up, our work is based on the analysis of over 70,000 posts, where approximately 26,737 have been published using 12,071 distinct Twitter accounts, and almost 49,658 from 6,746 Facebook ones.

### IV. CD COMMUNITY MEMBER ACTIVITY

Our first aim has been that of understanding how activity patterns eventually differed between the two OSNs during the given periods. The starting point has been that of verifying whether their activity follows a power law

distribution. To this aim, the use of different observation periods (i.e., Facebook activity covers 2 years vs. 6 months of Twitter activity) did not jeopardize our analysis. We applied the *goodness-of-fit* test, generating a p-value that quantifies the plausibility of the othesis [15].

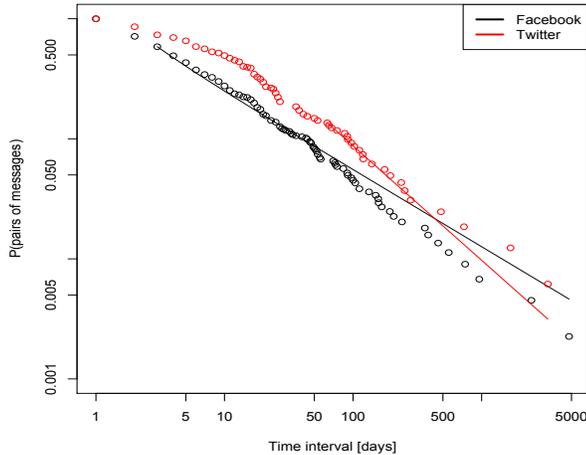


**Figure 1. Distribution of posted messages per member vs. power law ideal behavior**

Such test computes the distance between the ideal and the empirical model: a p-value close to 1 implies that the power law model plausibly fits the data. We obtained p-value = 0.43 for Facebook and p-value = 0.77 for Twitter, yielding a Twitter activity behavior that is more closely represented by a power law model, following the same behavior noted in other studies on the World Wide Web and social media, e.g.: [16]. This difference may be further appreciated in Figure 1: Facebook activity departs from the ideal power law model between 20 and 50 messages, value beyond which more members than those given by the power law model are present, while Twitter data more closely follows the power law distribution. Such difference is easily explained giving a more in depth look at the data: Facebook pages activity lion share is detained by their page administrators, as opposed to Twitter where no specific page is devoted to CD and hence posting activities occur in a flat style.

The first lesson we here learn is that although the two OSN are open to comments and discussions regarding CD, a rather restricted group of people (i.e., professionals and patients) is responsible for a large share of information that may be found on Facebook, but also on Twitter: the top ten Facebook users posted 4,050 messages (~8%) vs. the 1,366 tweets (~5%) written by the top ten Twitter users. A second metric of interest that illustrates the degree of activity of users is inter-post time. With inter-post time we indicate the time a given author of a first post takes to write a subsequent one. Again, we see that subsequent messages are typically concentrated during the same day, evidently driven by topics and discussions where an exchange of ideas and opinions occurs with other users (Figure 2). Twitter exhibits a behavior more closely represented by a power law decay model (p-value = 0.69), as opposed to

Facebook (p-value = 0.01), confirming the trend observed [16]. On the other hand, both Twitter (~69% of cases) and Facebook (~63% of cases) users follow a pattern where successive posts are typically published within a week one from the other. All in all, after a first analysis that is solely based on simple indicators such as number of members, number of messages and frequency of messages, we find that both Facebook and Twitter exhibit a skewed pattern, where only 261 and 201 users, respectively, post at least 10 messages.



**Figure 2. Inter-post time per member distribution vs. power law ideal behavior**

#### IV. MEDICAL TOPICS

Clearly, it is natural to expect that a platform of over 70,000 posts may contain all types of topics, including gossip and recipe sharing. For the purpose of our work, we confronted with a team of CD professionals in order to limit our search. In particular, we limited to individuate when a given post touched upon one of the 4 different areas of discussion: causes, symptoms, treatments and side effects, topics that are implicitly related among each other.

##### A. Topics Filtering on OSNs

The first problem that has been addressed was that of creating a software system that could tell whether a given post touched one of the 4 given topics, or not. To do this, we built 4 distinct dictionaries (1 for each of the 4 arguments of interest) where we grouped all those terms whose appearance/absence could indicate topic memberships. The dictionaries have been filled: (a) creating a list of all the significant terms (verbs and nouns) that appeared at least 50 times in the 2 given OSNs, and, (b) assigning to a given topic all those terms that signaled its appearance (e.g., the term *infection* could indicate that given symptoms are being discussed). In Figures 3 and 4 we list the terms that have been found on the 2 OSNs from the 4 dictionaries of interest. In general, as expected, more terms have been individuated for Facebook than for Twitter, as in the former OSN posts are not limited in length as in latter one. Exploring more in detail the terms

that have been included in each of the *causes* and *symptoms* dictionaries, we find that in the first nutrition terms prevail (e.g., *pasta, eggs, milk, chocolate*, etc.), while in the second one terms can describe specific symptoms (e.g., *fever*), but also represent anatomical parts (e.g., *rectum*) or states of pain and distress (e.g., *suffer*).

	Facebook	Twitter
Cause	Alcohol, bacteria, butter, cake, cell, chocolate, coffee, drink, eggs, food, gene, honey, lactose, map, meat, milk, pasta, smoke, sugar, tnf, virus, vitamin, wine.	Bacterium, bovine, celiac, cows, eat, epstein, food, gluten, lupus, meat, milk, parkinson, smoking, stress, tourette, virus.
Disease	Abdomen, abscess, agony, anal, anxiety, appetite, arthritis, attack, belly, bladder, bleed, blood, bone, bowel, butt, colitis, constipation, cramp, damage, deficiency, depression, diabetes, diarrhea, digestion, disorder, exhausted, fever, fever, fistula, flare, flu, gastro, grow, hurt, infection, inflamed, intestine, liver, mouth, muscle, nausea, pain, psoriasis, rectum, scar, severe, sleep, stress, suffer, symptom, tired, toilet, ulcer, vomit.	Appetite, arthritis, bathroom, bipolar, blood, bowel, cancer, chronic, cobblestone, colitis, colon, colorectal, cystic, depression, digestive, disability, disorder, dysfunction, epilepsy, esophagus, fibromyalgia, fibrosis, flare, flu, gastrointestinal, inflammation, intestine, irritable, issues, leukemia, mouth, ms, pain, problem, purple, severe, stomach, suffer, syndrome, ulcerative, weight.

**Figure 3. Causes and symptoms dictionaries**

In the *treatments* dictionary, instead, we find the lion share is taken by pharmaceuticals (e.g., *azathioprine, infliximab, humira, pentasa*, etc.) and by other generic terms related to the medical care of CD (e.g., *operation, specialist, solution, dose*, etc.). Finally, the *side effects* dictionary includes only a few terms, typically of very general sense (i.e., *effect* and *allergy* in Twitter), whereas only one refers to a specific pathology (i.e., *lupus*).

##### B. Topics Mix

Once all terms have been processed and have found a place in or out one of the 4 dictionaries, we proceeded assigning posts, when possible, to at least one of the 4 possible groups: causes, symptoms, treatments, side effects. Figure 6 and 7 provide a visual representation of the topic mix of the 4 topics of interest as detected on the 2 considered OSNs. In particular, Figure 6 reveals that approximately 60% of Facebook posts contain terms pertaining treatments or symptoms vs. only 10% and 25% percent of posts related to side effects and causes, respectively. In Figure 7, instead, a strong bias towards symptoms emerges (approximately 90% of tweets contains at least one term contained in the symptoms dictionary).

	Facebook	Twitter
Treatment	Adalimumab, aloe, antibiotic, asacol, azathioprine, budesonide, calcium, cannabis, capsule, certolizumab, cimzia, colectomy, colonoscopy, colostomy, diagnosis, diet, doctor, dose, drain, entocort, enzyme, fda, ferment, ginger, gp, healthcare, hospital, humira, ileostomy, imuran, infliximab, infusion, injection, kefir, marijuana, medication, medicine, mercaptopurine, methotrexate, morphine, mri, natural, nutrition, operation, oral, organic, paleo, pentasa, powder, prednisolone, prescribed, prescription, probiotic, rafton, remedy, resection, reversal, scd, solution, specialist, steroid, surgeon, surgery, test, therapy, transplant, treat, visit.	Adalimumab, benefit, biologic, cannabis, care, check, clinical, cure, diet, drug, endoscopy, fight, floriset, gpg, healing, healthy, hemp, humira, ileostomy, infliximab, inhaled, marijuana, med, mmj, pill, placebo, qu, remission, sgx203, solligenix, supplement, surgery, therapy, treat, vaccine, weed.
Side effect	Complications, effect, lupus, reaction allergy, skin.	Allergy, effect.

**Figure 4. Treatments and side effects dictionaries**

##### C. Topics vs. Authors

Our attention now concentrates on understanding whether any dependency or trend existed between the amount of activity of an author and his/her topic mix. The observations made for Figures 5 and 6 are confirmed in

Figures 7 and 8 where, for both OSNs, we plot the distribution of topics for the 100 most prolific authors: we find that the general behavior pattern does not visibly change for either site as a function of posted messages.

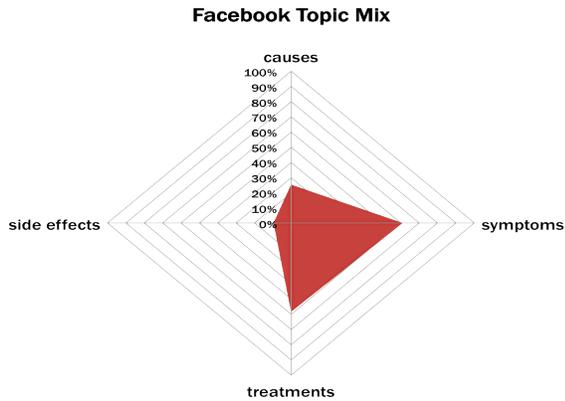


Figure 5. Facebook topic mix

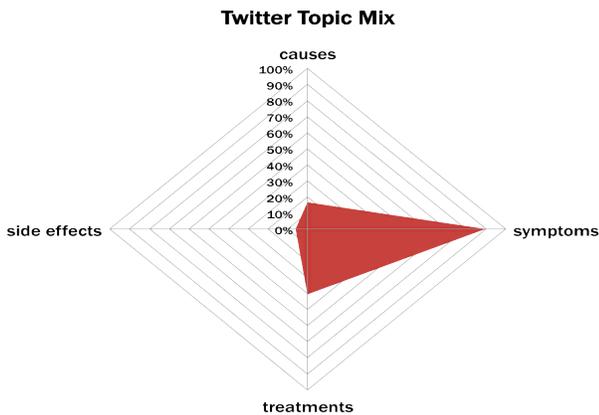


Figure 6. Twitter topic mix

Such result remains also valid, on average, when extending such analysis to all the remaining authors. Our analysis has then proceeded as follows: we worked at a finer classification of the 20 most prolific authors (i.e., patient, advertisement, etc.) reading the content presented in their posts. The messages posted by these 2 groups of authors represented approximately the 12% and 8% of the total messages that could be found during the given periods on Facebook and Twitter, respectively. With this we note that their weight is not at all irrelevant and may give us an additional perspective on the information found on the 2 given SNs. Figures 9 and 10 show the results of this analysis: the majority of these Facebook users may be classified as patients, whereas the majority of Twitter's as advertisement. In fact, we found that Facebook authors typically shared personal experiences, while tweets generally shared scientific literature news or fund raising campaign information related to CD. For example, a tweet that contained the words *smoking* and *marijuana* was re-tweeted over 580 times (such tweet reported the results of a

study regarding the role marijuana could play to facilitate CD remission phases).

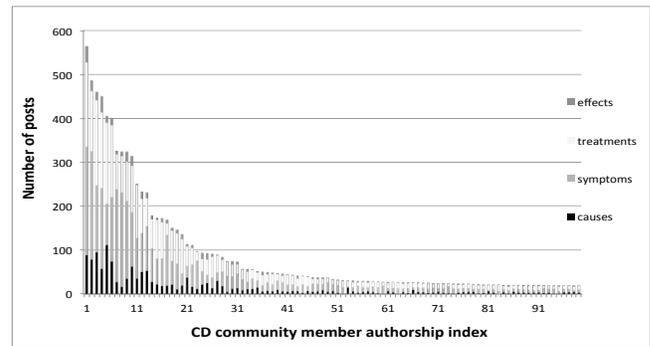


Figure 7. Topic mix of the 100 most active Facebook users

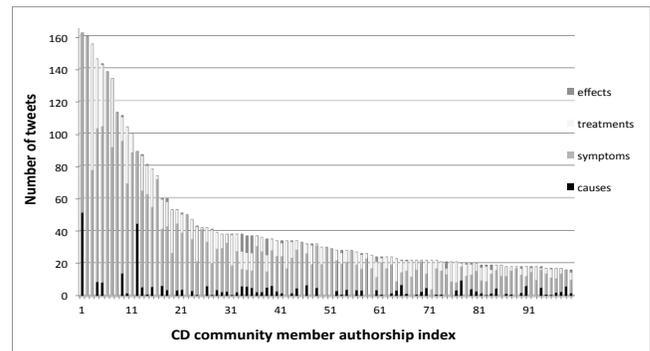


Figure 8. Topic mix of the 100 most active Twitter users

Other tweets that have been frequently shared discussed the influence that given food could have on the remission/appearance of CD's symptoms.

#### D. Topics Relations

In light of these results, rather than focusing on the type of information that could be found on Twitter, as we had a strong indication that an important share of such information would not directly originate from patients, we concentrated our efforts on studying more in depth the data that could be mined from Facebook posts. With this in mind, we moved one further step ahead. Inspired by the relations that ideally connect causes with symptoms, symptoms with treatments and treatments with side effect, we sought to understand how closely related were the terms reported in the 4 different dictionaries.

Type of Author	Period of Activity	Type of Author	Period of Activity
Admin, Patient	18/11/2012 - 25/10/2013	Admin, Event	15/03/2012 - 13/10/2013
Admin, Patient	04/05/2012 - 08/10/2013	Admin, Patient	02/11/2011 - 01/10/2013
Admin, Patient	27/10/2011 - 25/10/2013	Admin, Patient	14/02/2012 - 16/10/2013
Admin, Patient	16/05/2012 - 25/10/2013	Admin, Event	27/10/2011 - 25/10/2013
Admin, Patient	29/06/2012 - 18/10/2013	Admin, Donation	19/05/2011 - 09/10/2013
Admin, Patient	09/11/2012 - 25/10/2013	Admin	23/11/2011 - 21/10/2013
Admin, Scientific Articles, Advertisement	26/03/2012 - 23/10/2013	Admin	03/08/2012 - 19/10/2013
Admin, Patient	24/09/2012 - 25/10/2013	Admin	18/09/2012 - 24/10/2013
Admin, Scientific Articles, Advertisement	31/10/2011 - 25/10/2013	Admin	02/05/2012 - 15/10/2013
Admin, Patient	17/07/2012 - 25/10/2013	Admin, Patient	27/10/2011 - 23/10/2013

Figure 9. The 20 most prolific Facebook users

Type of Authors	Period of Activity	Type of Authors	Period of Activity
Awareness, Advertisement	30/04/2013 - 25/10/2013	Donations, Event	30/04/2013 - 25/10/2013
Donations, Advertisement	04/06/2013 - 05/08/2013	Scientific Literature	08/05/2013 - 23/10/2013
Scientific Literature, Advertisement	30/04/2013 - 26/10/2013	Patient, Scientific Literature	30/04/2013 - 19/10/2013
Scientific Literature, Advertisement	30/04/2013 - 06/08/2013	Literature, Advertisement	10/05/2013 - 23/10/2013
Scientific Literature, Advertisement	30/04/2013 - 06/07/2013	Scientific Literature	01/05/2013 - 26/10/2013
Donations, Advertisements	03/05/2013 - 06/08/2013	Donations, Event	19/05/2013 - 02/10/2013
Blogger, Advertisements	11/05/2013 - 14/07/2013	Scientific Literature	01/05/2013 - 18/07/2013
Donations, Advertisements	30/04/2013 - 05/08/2013	Scientific Literature	18/05/2013 - 24/10/2013
Patient	12/05/2013 - 24/10/2013	Event	30/04/2013 - 14/06/2013
Celebrities suffering Crohn's disease	01/05/2013 - 26/10/2013	Scientific Literature	30/04/2013 - 09/06/2013

**Figure 10. The 20 most prolific Twitter users**

In particular, we resorted to an approach, where we sought for: (a) how often a given symptom appeared conditioned to the appearance of a given cause, (b) how often a given treatment appeared conditioned on symptoms, and, (c) how often side effects conditioned on treatments. In other words, with the adoption of such methodology, we computed how frequently a given term appeared (e.g., a treatment), when a certain term, taken from another dictionary, was present (e.g., a symptom). In Figures 11 and 12 we show the results of this analysis, limiting to those that exhibit a conditional frequency greater or equal to 0.25 (e.g.,  $F(A|B) = 0.25$  indicates that word A appears in the 25% of posts where term B appears). Interestingly, we can deduce the following from this data: CD patients discuss which might be the cause of their health disorder, focusing on bacterial, genetic and vitamin deficiency explanations. It is also interesting to note that not as much attention is devoted, instead, to the discussion of specific diets or foods that may be causing an increase of the incidence of such disease. The information reported in Figure 12, instead, witnesses that generic symptoms are usually associated with the idea of taking a test, while more specific ones often include a discussion of surgical solutions. In the following we will move one additional step forward, trying to find not only how people behave online, but also working on understanding how people feel about given arguments of interest.

Facebook subtopic	symptom   cause	F(symptom   cause)	symptom   cause	F(symptom   cause)
Immune system	disease   bacteria	0.65		
Genetic	disease   gene	0.43	disease   cell	0.31
Diet	vitamin   deficiency	0.53		

**Figure 11. Relations between causes and symptoms**

Facebook subtopic	treatment   symptom	F(treatment   symptom)	treatment   symptom	F(treatment   symptom)
Exams	test   inflamed	0.36	test   constipation	0.31
	test   damage	0.36	test   liver	0.29
	test   blood	0.34	test   abdomen	0.28
	test   diarrhea	0.31	test   disorder	0.26
	test   deficiency	0.31	test   rectum	0.25
Surgery	surgery   abscess	0.36	surgery   bladder	0.27
	surgery   scar	0.33	surgery   abdomen	0.26
	surgery   fistula	0.32		
	surgery   rectum	0.27		

**Figure 12. Relations between symptoms and treatments**

## V. MOOD VS. PHARMACOLOGICAL TREATMENTS

Although the analysis that we have proposed to this point gives us some interesting pieces of information, like the fact

that important shares of CD patients resort to Facebook rather than to Twitter, for example, or the fact that patients devote most of their time, while posting on such OSNs, discussing treatments and symptoms, much more can clearly be done. OSNs can be, for example, locations where we not only assess the topics that people are most interested at, but also locations where we measure how (and in which terms) people talk about given arguments. Could we, for example, discover how positively, or negatively, people consider a given treatment from their posts online? Or, could we find that the mood that patients express online is influenced by the use of given medications (i.e., such information might be beneficial for the support of patients that are undergoing given treatments)?

### A. Mood vs. Pharmacological Treatments: Correlation

How different patients respond to given medications is clearly a subject of intense research in the area of CD [17]. We here, instead, aim at understanding the attitude patients typically express when citing given medications/treatments. To fulfill this aim we first of all grouped together all the medications that corresponded to the same active ingredient, as the same active ingredient may be commercialized in different countries utilizing different names. We hence individuated the following groups by active ingredient: (a) 6-Mercaptopurine (6MP), (b) Adalimumab, (c) Azathioprine, (d) Beclometasone, (e) Budesonide, (f) Certolizumab, (g) Infliximab, (h) Mesalazine, (i) Methotrexate, (l) Methylprednisolone, (m) Natalizumab, and, (n) Prednisone. Utilizing such information we extracted the time series that described how much and how often such groups were mentioned on Facebook. While simple ways exist to measure how frequently users cite given medications or surgical terms in Facebook, assessing a user's attitude from a post is not as trivial. In order to perform such type of analysis we resorted to known subjectivity analysis techniques. In particular, we utilized *OpinionFinder*, a system that can process a corpus of text and identify subjective sentences as well as various aspects of subjectivity within sentences (i.e., agents who are sources of opinion, direct subjective expressions and speech events, and sentiment expressions) [18]. When processing a post, *OpinionFinder* returns the sentiment of each phrase that composes it, classifying it as neutral, positive or negative. *OpinionFinder* can be used to measure how the mood expressed in posts evolves in time, when discussing on a given topic.

In Figures 13, 14 and 15 we plotted the sentiment evolution for the groups that have been cited at least 20 times. In order to visualize the sentiment evolution for each particular treatment with a single graph, we computed the sentiment value as the difference between the positive and negative sentiments expressed during a week. Say, for example, that *OpinionFinder* finds 10 positive sentiments and 4 negative ones in the messages posted during a week, the sentiment value for that week would be 6. Hence, a

positive (negative) value on the graph corresponds to an overall positive (negative) sentiment during a given week. After a quantitative analysis of these graphs we can conclude what follows: although moods alternate at a frequent pace when the post discussion touches upon Azathioprine and Adalimumab, positive opinions appear more present than negative ones. We also see that users talking about 6MP, Budesonide, Certolizumab, Mesalazine and Prednisone typically maintain a neutral opinion, with the exception of a few positive and negative spikes, more or less equally distributed, that do not let us decide for a predominant positive or negative mood. Methotrexate exhibits a pattern where the general mood is negative at the beginning, very positive at the center of our observation period and again negative at the end. Finally, while the discussion about Infliximab appears neutral for a long time, it fires up at the end, with positive sentiments dominating over negative ones. As a further check, we verified which were the positive and negative words that appeared most frequently together with the treatments of interest (Figure 16). Such information (positive terms are again associated to positive count values, and negative terms to negative count ones) does give a quite exhaustive understanding of the ongoing discussion that is associated to treatments (both in positive and negative terms). Again Adalimumab, Azathioprine and Infliximab emerge as the medications that are the leading arguments of interest for CD patients.

### B. Mood vs. Pharmacological Treatments: Time Series Analysis

In the light of the results obtained in the preceding subsection, we concentrate on the three aforementioned treatments that ignited most online debates. We change point of view, as after assessing the opinions that people clearly express when discussing a given treatment we are interested now in understanding whether a relationship may be established between the discussion on a given treatment and the general mood subsequently experienced by patients who took part in that discussion. In essence, we are puzzled by the same problem a physician faces when testing a new therapy on a patient. *How will patients' conditions* (i.e., physical, but also psychological) *be affected?* The difference being we cannot directly measure physiological parameters but only sentiments.

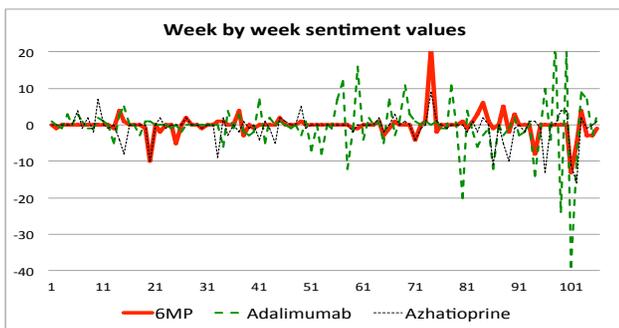


Figure 13. 6MP, Adalimumab and Azathioprine

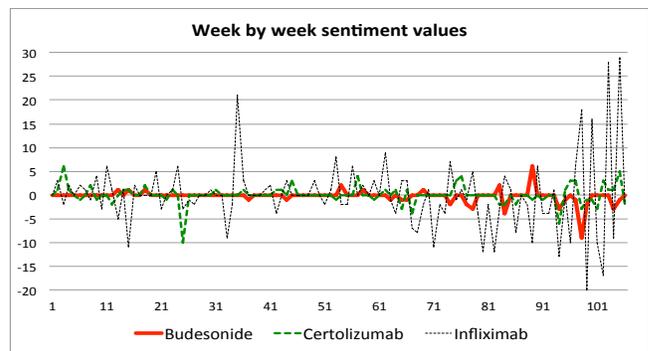


Figure 14. Budesonide, Certolizumab and Infliximab

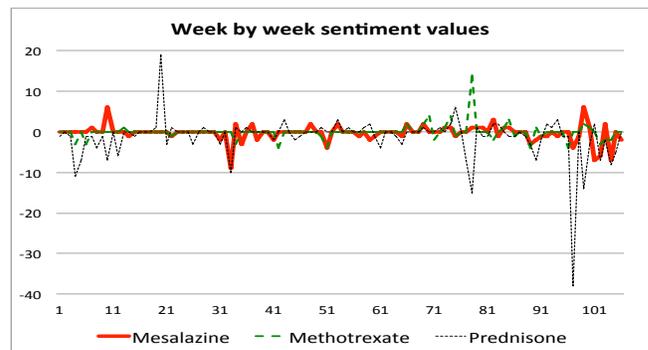


Figure 15. Mesalazine, Methotrexate and Prednisone

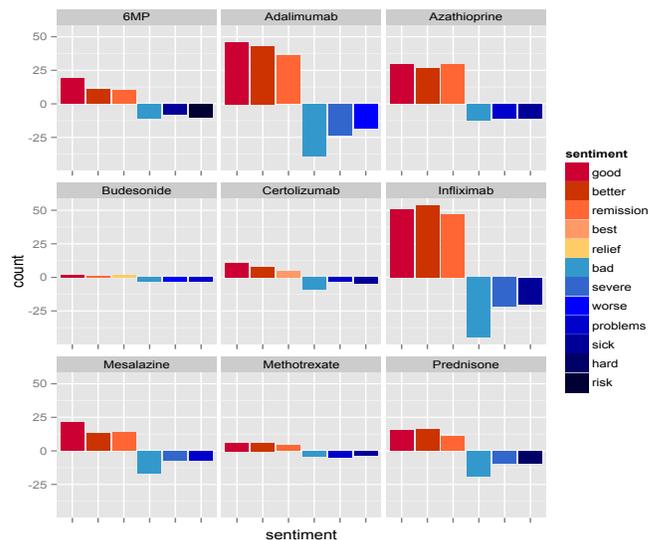
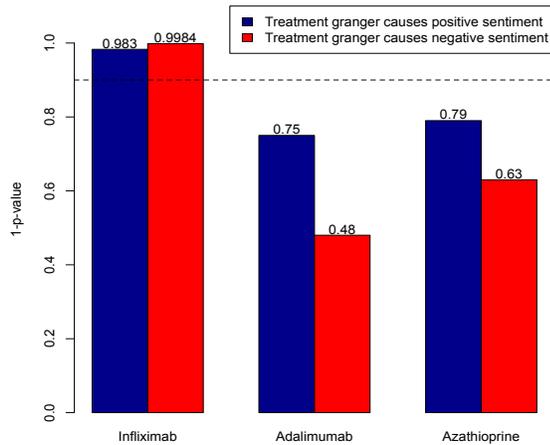


Figure 16. Positive and negative words per treatment

Hence we transpose the question as follows: is it possible to find a causal relationship between the general mood that a patient expresses at a given moment and the fact that she/he has previously taken part in a discussion on a given medication? Clearly, an important assumption here is that we are assuming that anyone discussing a given treatment online is actually taking that medication. To proceed with this analysis, we suppose the following pattern of behavior exists: (a) at time  $t_1$  a given patient, say A, inquires the OSN asking whether anyone has been on a

given prescription, (b) at time  $t_2 > t_1$  the discussion on that specific prescription develops even with contributions by other users and (c) at time  $t_3 > t_2$  we measure the feelings that patient A shares online when engaged in any general discussion (not specifically related to that given treatment). Technically, we look for any existing causal relations between the pharmacological treatment discussions time series and the sentiment time series (positive and negative ones).



**Figure 18. Top-3 positive and negative sentiments**

In fact, the correlations we sought in the previous sections do not prove causation: we hence resort to Granger causality analysis to check whether one time series provided predictive information about the other [19]. Granger causality analysis establishes the dependence between two temporal variables. For the sake of brevity we move directly to the results, taking as the treatment time series their weekly count and as positive and negative sentiment time series the weekly values computed utilizing *OpinionFinder* on all the posts that appear on CD pages. We resorted to the Toda-Yamamoto method to take care of the non-stationary nature of the signals under study [20]. In Figure 6, we plot the (1-p) value obtained for all the three medications of interest as a cause of positive and negative moods, (1-p) being in practice the probability that such a relationship exists. Examining the results, we observe that non negligible correlation probabilities exist for all the medications; nonetheless according to the Granger theory, a relevant statistical significance may be established only for p values  $< 0.1$ , hence validating only Infliximab as a possible source of positive and negative moods among CD patients. Concluding, while we started the last part of our analysis asking an ambitious question (i.e., *is the mood that patients express online influenced by the use of given medications?*), we here ended with an interesting direction for future studies. It seems that Infliximab is the treatment that is predominantly influencing the CD community.

## VI. CONCLUSIONS

This work focused on understanding the OSN ecosystem of a particular class of chronic diseases patients, CD ones. OSN posts revealed a rich ongoing discussion, especially around treatments and symptoms. We dissected such discussion and learned that Infliximab is the treatment that mostly influences the CD community sentiments.

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