UNDERSTANDING ONLINE HEALTH ISSUE-FOCUSED COMMUNITIES WITH TEXT MINING

An exemplary analysis of a German limestone forum with more than 4,800 threads and 100,000 posts

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> *"Without love we could not survive. Human beings are social creatures, and a connects for each other is the very basis of our life together."*
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> — *Thich Nhat Hanh, 14th Dalai Lama*

Introduction

From the perspective of a market researcher interested in human behavior, the majority of existing data is low online. While this is in some way very convenient, it also poses some challenges. The challenges are that it is lot of the data exists in a very unstructured format that is not designed to answer the kind of questions we are interested in, and it the sheer amount and complexity of data can be overwhelming.

The classic online forum (or message board) is an often overlooked social media platform that offers some interesting advantages to tackle these challenges, however. First of all, the forum usually already ventures around a topic of interest, that can be anything ranging from films to vintage sports cars to medical issues. Secondly, the structure of the forum is a fairly simple and a hierarchical one: The main forum is usually divided into sub-forums that zoom deeper into some aspect of the general topic, and the sub-forums then consist of discussion threads that in turn consist of posts by individual users. The users create the context of the forum by starting, and participating in, discussion threads on specific topics. Importantly for the users, the forum is also a community and can act as a source of emotional as well as informational support, which is especially relevant in the case of forums centered around health issues.

Online forums and advanced text analytics are one way to utilize the cornerstones for understanding a specific community or target group. In this blog post, we demonstrate the use of text mining[1] as an online research method for gaining insight into the topics and trends that move the users of a medically focused online community. We discuss relevant characteristics and meta-information of the online-forum and the role of prominent users as opinion leaders. Although not demonstrated here extensively, the approach could easily be extended to answer further, more focused, questions on trending topics, mentions and sentiments regarding treatment options, and relevant products such as medications.

Background & Data

The analyzed online-forum is popular among people who, either temporarily or permanently, have an artificial bowel outlet, or in medical terms, an ileostomy. There are multiple reasons why such a surgical opening becomes necessary, however, patients who suffer from severe inflammatory bowel disease (IBD), specifically ulcerative colitis and Crohn's disease, are often reminiscent of an ileostomy and the necessary ostomy pouch to collect intestinal waste. In any case, when drug treatment options are exhausted and the bowel must be removed, an ileostomy becomes indispensable. The procedure is of course a very invasive one, and marks a major life change for the patient undergoing it, so it's easy to see how a community of people in the same situation would be an invaluable resource.

The forum was founded in 2003 and changed ownership in 2010. Today, the forum follows a classic online forum format and is mentioned in two parts: (1) a public forum that consists of 7 sub-forums, in which every internet user can read, but only registered users can write, and (2) a private forum with 5 sub-forums, where only registered users can read and write.

As part of our text mining approach, we use web scraping to automatically and iteratively extract, collect and store the needed text content and meta-information of the public forum at one point in time[2]. The resulting data structure builds the foundation for our analysis and understanding of the community up to that point. Across all 7 sub-forums of the public section of the forum, we extracted 4,894 threads, inheriting 104,643 posts in total.

Results

The community is diverse in its topics and reflects that receiving an ostomy pouch touches on nearly every aspect of life. At IQ, we have been researching IBD-related online communities for several years but are keen to learn more about limestone patients specifically.

We find that users come to the forum to ask for advice on day-to-day challenges, treatment options and advances, to share experiences, and to offer support to others in similar situations. This is reflected by the topics of the most discussed or active threads (see Figure 1). Of each sub-forum, as depicted in the treemap below. The visualization is interactive: you can scroll, click and drag. The names of the sub-forums and threads are in German, the original language of the community.

Popular subforums: Everyday life, reversal surgery, illnesses & therapies
Most discussed threads by subforum

Exploring the Top-15 of all-time threads, we discover challenges of everyday life with ilge on how to master them, emotional patient stories, support requests, requests for information on bureaucratic processes and also threads that build a community.

To learn more about the community, we broaden our perspective and also look at the all-time Top-20 threads of the forum as a whole.

Popular threads deal with coping with fears and comorbidities, e.g., cancer
Top 20 threads
Stoma Alltag
Ileostomie
Angst vor Krebs
Angst vor Krebs
Ileostomie gesetzt
Ileostomie gesetzt
Gehört ich zu wenig?
Tumorsuche
Ileostomie Angst
Ileostomie Angst
Ileostomie Angst