

To Study Social Media Conversations Concerning IBD
Support Programs in USA

By

Ila Bhatia

*Dissertation submitted for the partial fulfillment of the
MBA Hospital and Health Management*

Academic year, 2016-2018



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TO WHOMSOEVER MAY CONCERN

This is to certify that Dr. Ila Bhatia, a student of MBA Hospital and Health Management/
Pharmaceutical / Rural Management from The IIHMR University, Jaipur has undergone internship
training at SA Tech. for ZS Associates, Gurgaon, from February 05, 2018 to May 04, 2018.

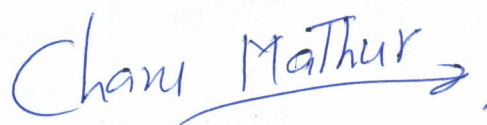
The Candidate has successfully carried out the study designated to him during internship training and
his approach to the study has been sincere, scientific and analytical.

The Internship is in fulfillment of the course requirements.

I wish her all success in all his future endeavors.



Dean, Academics and Student Affairs
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Assistant Professor
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Knowledge Management – ZS Associates

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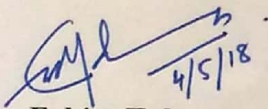
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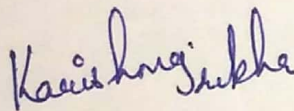
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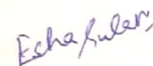
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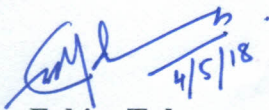
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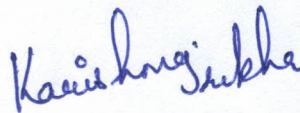
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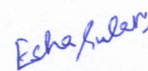
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CERTIFICATE BY SCHOLAR

This is to certify that the dissertation titled 'To study social media conversations concerning IBD Support Programs in USA' and submitted by Dr. Ila Bhatia, Enrollment No. 0421/MBAHM21 under the supervision of Dr Charu Mathur, for award of MBA in Hospital and Health/ Pharmaceutical / Rural Management in Health and Hospitals of the University carried out during the period from February 05, 2018 to May 04, 2018 embodies my original work and has not formed the basis for the award of any degree, diploma associate ship, fellowship, titles in this or any other institute or other similar institution of higher learning.



Dr. Ila Bhatia

Abstract

Social listening is the process of collecting data from social platforms and forums on a chosen topic. This could be a brand, an industry segment or anything at all. The collected data is then analyzed to find trends and useful insights. This can influence a wide range of processes including business operations, product updates, and advertising approaches.

Our main focus is perception of patients on IBD and the related support services. The patients are initially not that well aware about the disease. They use the social media for getting educated about the disease, it's signs and symptoms, the various drug regimens that are available for the same, and their respective efficacies and side-effects. The patients and their caregivers are also happy to post both their progress and problems online.

The patients and their caregivers use all types of media at their disposal and post content in various forms such as pictures, videos, infographics and textual content online. They use a variety of social media platforms such as Instagram, Twitter, Forums and Blogs, Facebook, YouTube and the like.

The study would help the Pharmaceutical Companies having focus on Inflammatory Bowel Disease understand the patients' perceptions and their needs in the segment, so that they can better cater to the same in the future.

ACKNOWLEDGMENTS

On the very outset of this report, I would like to extend my sincere and heartfelt obligation towards all the people who have helped me in this endeavor. The internship opportunity with ZS Associates, Gurgaon was a great chance for learning and development.

First and foremost, I would like to express my sincere gratitude to Mr. Nitin Aggarwal, Principal, KM team.

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I would also like to express gratitude to my college The IIHMR University, Jaipur for arranging summer training in good schedule. I also extend my gratitude to Col. Dr.(Retd.) Ashok Kaushik (Dean-Academics) and my project guide Dr. Charu Mathur (Assistant Professor) for their cooperation, help and encouragement.

Dr. Ila Bhatia

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List of Symbols and Abbreviations

Abbreviation	Meaning
UMass	University of Massachusetts
PMSA	Pharmaceutical Management Science
B2B	Business to business
ROI	Return on investment
IBD	Inflammatory bowel disease
FDA	Food and Drug Administration

Introduction

In recent years, the rapid expansion in internet access and computer-mediated communication has fostered new opportunities for individuals with health-related concerns to participate in supportive communication within a network of individuals dealing with similar issues¹.

An appropriate way to access and understand the above is through Social Listening. Social Listening is defined as primary research which involves extracting, structuring & analyzing social and other online media to come up with useful insights. It is the process of monitoring digital conversations to understand what customers are saying about either a therapy area, or a brand or an industry segment, online.

Social listening is primarily used for community management, such as identifying customer pain points and providing direct consumer response to questions, complaints, and comments. It is also used to surface feedback that could help to differentiate their brand, product, or service. Social media has the potential to become a tool, as it is a space where you can listen to individuals, on a micro level. Through use of data and social media listening tools, one can seek an understanding and insights into a variety of issues.²

It has come to prominence in recent times as analysis has revealed four primary needs for participating in groups within Facebook: socializing, entertainment, self-status seeking, and information. These gratifications vary depending on user demographics such as gender, hometown, and year in school. The analysis of the relationship between users' needs and civic and political participation indicated that, as predicted, informational uses were more correlated to civic and political action than to recreational uses.³ Participation in online communities is also often driven from the users' need for help. This help can be given by peers who have had similar experiences, and by professionals who participate in the discussions as moderator⁴.

The advent of the internet has created online support systems for social participation. However, minimal research has been conducted about determinants of individuals' in-person and online social participation or types of social participation which contribute to emotional well-being.⁵ Traditional survey methods are limited in the study of hidden populations due to the hard to access properties, including lack of a sampling frame, sensitivity issue, reporting error, small sample size, etc.

The rapid increase of online communities, of which members interact with others via the Internet, have generated large amounts of data, offering new opportunities for understanding hidden populations with unprecedented sample sizes and richness of information.⁶

Social listening, in the context of public health sometimes called infodemiology or infoveillance, is the process of identifying and assessing what is being said about a company, product, brand, or individual, within forms of electronic interactive media.⁷ To better understand trends in attitudes and behaviors, public health and communication professionals can turn to the dialogue taking place on popular social media platforms. Analyzing social media trends is a meaningful way to inform public health practitioners of current sentiments.⁸

The therapy area which has been focused upon in this report is inflammatory bowel disease.

Inflammatory bowel disease (IBD) is an umbrella term used to describe disorders that involve chronic inflammation of your digestive tract.

Types of IBD include:

- Ulcerative colitis. This condition causes long-lasting inflammation and sores (ulcers) in the innermost lining of your large intestine (colon) and rectum.
- Crohn's disease. This type of IBD is characterized by inflammation of the lining of your digestive tract, which often spreads deep into affected tissues.

Both ulcerative colitis and Crohn's disease usually involve severe diarrhea, abdominal pain, fatigue and weight loss.

IBD can be debilitating and sometimes leads to life-threatening complications.

Inflammatory bowel disease (IBD) is a chronic gastrointestinal condition affecting over 5 million people globally and 1.6 million in the United States but currently lacks a precisely determined cause or cure. The range of symptoms IBD patients experience are often debilitating, and the societal stigmas associated with some such symptoms can further degrade their quality of life. Better understanding the nature of this public reproach then is a critical component for improving awareness campaigns and, ultimately, the experiences of IBD patients.⁹

The genuine, nonmedically influenced patients' opinion obtained from Facebook pages can be easily reviewed by experts from different research backgrounds, with a substantial agreement on the classification of patients' sentiment. described method allows a fast collection of big amounts of data, which can be analyzed to gain insight into the patients' perspective on a specific medical therapy.¹⁰

Social media reveals a wide range of themes governing patients' experience and choice with IBD biologics. The complexity of navigating their risk-benefit profiles suggests merit in creating online tailored decision tools to support IBD patients' decision-making with biologic therapies.¹¹

Objective:

- To develop an understanding for the patient support features and services available to patients across the IBD ecosystem using patient and caregiver conversations.

Literature Review

Coulson in their study on 'Computer-mediated support group for individuals living with Irritable Bowel Syndrome' expressed that expansion in internet access and computer-mediated communication has fostered new opportunities for individuals with health-related concerns to participate in supportive communication within a network of individuals dealing with similar issues.

Cole-Lewis et al. in their study on 'Content Analysis of E-Cigarette Discussions on Twitter' concluded that, social media has the potential to become a tool, as it is a space where can you listen to individuals, on a micro level. Through use of data and social media listening tools, one can seek an understanding and insights into a variety of issues.

Park et al. in their paper on 'being immersed in social networking environment: Facebook groups, uses and gratifications, and social outcomes' analyzed the relationship between users' needs and civic and political participation and indicated that, as predicted, informational uses were more correlated to civic and political action than to recreational uses.

Cipolletta et al. in their paper titled 'online support for transgender people: an analysis of forums and social networks', found that participation in online communities is often driven from the users' need for help. This help can be given by peers who have had similar experiences, and by professionals who participate in the discussions as moderators.

Chuchu et al. in their paper titled 'hidden populations online: topic, emotion, and social network of HIV-related users in the largest Chinese online community' stressed that, the rapid increase of online communities, of which members interact with others via the Internet, have generated large amounts of data, offering new opportunities for understanding hidden populations with unprecedented sample sizes and richness of information.

Anderson et al. in their paper titled 'using social listening data to monitor misuse and nonmedical use of bupropion: a content analysis' found that in the context of public health is the of identifying and assessing what is being said about a company, product, brand, or individual, within forms of electronic interactive media.

Moorley et al. in their paper titled 'developing nursing leadership in social media' concluded that, to better understand trends in attitudes and behaviors, public health and communication professionals can turn to the dialogue taking place on popular social media platforms. Analyzing social media trends is a meaningful way to inform public health practitioners of current sentiments.

Groshek et al. in their paper titled ‘media consumption and creation in attitudes toward and knowledge of inflammatory bowel disease: web-based survey’ found that range of symptoms IBD patients experience are often debilitating, and the societal stigmas associated with some such symptoms can further degrade their quality of life. Better understanding the nature of this public reproach then is a critical component for improving awareness campaigns and, ultimately, the experiences of IBD patients.

Methodology

- The following social media platforms would be used for analysis
 - Twitter
 - Facebook
 - Instagram
 - Forums (patient and caregiver)
 - Blogs (patient and caregiver)
- Analysis would be done on a sample of patient and caregiver conversations of the population of US for the time period August, 2017 – January, 2018.
- For this study, the support services accessed by the patients would include:
 - Disease education
 - Advocacy
 - Side-effect monitoring
 - Symptom and lifestyle tracking
- Analysis Methodology (data pool and sample selection):
 - US based, Online, and public conversations are pulled using a social listening tool.
 - A specific keyword based query was developed based on the project objectives. Removal of noise and irrelevant data using algorithms and manual validation.
 - Manual editing, tagging, and validation by domain experts Stakeholder identification via proprietary algorithm.
 - A sample of conversations is taken using the following formula:
 - Using Stratified Random Sampling technique

$$n_0 = \frac{Z^2 \times pq}{e^2}$$

where:

- Z = the critical value of the Normal distribution (e.g. for a confidence level of 95%, the critical value is 1.96)
 - e = the margin of error (an error margin of 5%.)
 - p = the sample proportion, q= (1-p)
the value of p,q are being taken as 0.5 each
 - n0= sample size
- Specific analyses
 - Sentiment analysis
 - Frequency distribution
 - Metrics and qualitative findings are tied together to understand trends.

Results

1. Sample calculation:

Table No. 1.1: Conversation Distribution

Support Analysis Process	No. of Conversations
All conversations about Crohn's, UC and CC	346000
Conversations about Patient Support Programs	128000
Patients'/Caregivers' conversations about their support system	15000
Most relevant conversations analyzed (Relevant sample)	503

2. Disease distribution among the final set of conversations:

Table No. 1.2: Percentage distribution of disease mentions

Crohn's Disease	Ulcerative colitis	Chronic Constipation
73%	24%	3%

3. Channel breakup:

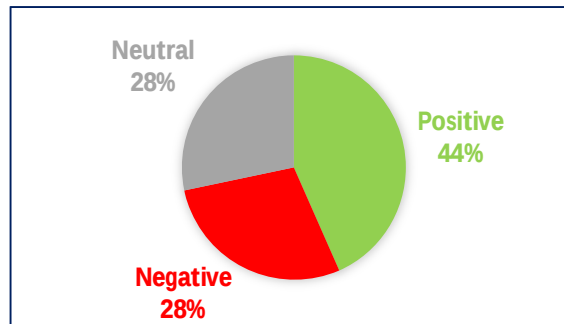
Table No. 1.3: Percentage distribution of channel usage

S. No.	Channel	Percentage (%)
1	Instagram	40
2	Forum	29
3	Twitter	15
4	Facebook*	10
5	Blog	3
6	Others	3

*Facebook only shares 2% of its entire data for analysis. Only open groups could be accessed for Facebook

4. Sentiment split:

Figure No. 1.1: Sentiment Split



5. Key takeaways:

a) Disease Education:

- When diagnosed patients have limited knowledge about what IBD is and how it will impact their life.
- Reading conversations posted by fellow patients and their caregivers helps them reach a certain comfort level. They realize that there are others who have been suffering from the same disease and have gone through similar experiences
- Some patients who have lived with the disease for extended time like to share their experiences to raise awareness and educate others. This helps others understand what is in store for them and how could they deal with the same.
- Patients discuss WebMD, Mayo Clinic, Crohn's and Colitis Foundation and other patient forums, as resources to help learn about the condition

b) Advocacy

- Advocacy groups help connect patients with other patients and caregivers in similar conditions.
- People feel positive as they get to meet and chat about their conditions with others who are going through a similar experience.
- People might also seek advice from others, or learn from their experience through the dedicated forums started by various advocacy groups

c) Symptom and lifestyle tracking

- Patients regularly keep track of their symptoms during the treatment phase and share them explicitly on social media. They share their journey with the disease, with either daily or event based updates.
- Diet and lifestyle maintenance is one of the most talked about topics in this phase. Diet tracking, their experiences, their recommendations about lifestyle patterns and related issues compose the content of their online posts.

d) Side-effect monitoring

- Patients are sharing their experiences concerning side effects.
- They are both asking for support and advising others on the possible side effects and their future course of action.
- Some patients and their caregivers are also directly posting the name of the drugs and the side-effects that they have been experiencing because of them. This also has significance in tracking of adverse drug events and their reporting to the FDA.
- It also helps to make the patients aware about the possible side-effects that they may face, before they start the drug regimen, by reading other patients stories and experiences.

Conclusion

Social listening is the process of collecting data from social platforms and forums on a chosen topic. This could be a brand, an industry segment or anything at all. The collected data is then analyzed to find trends and useful insights. This can influence a wide range of processes including business operations, product updates, and advertising approaches.

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