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Content Analysis of Online Patient Support Groups: Netnographic Approach

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INTRODUCTION

The concept of online communities lacks a clear and universally accepted definition in academic literature. Despite several efforts to characterize this phenomenon, one notable attempt by Rheingold describes virtual communities as social groups that develop on the internet through sustained public discussions, fostering significant human connections and forming networks of relationships in the digital realm (Rheingold, 2000). In the context of online communities, it's important to recognize that communication occurs through electronic means, without being constrained by specific locations or time zones. Additionally, these communities typically welcome new members, allowing them to sign up at no cost. Engaging in these activities provides individuals with a deeper understanding of their health conditions and the chance to establish connections with others facing similar circumstances (Meier et al., 2007; Lobchuk et al., 2015). Numerous online health communities exist, each with its distinct objectives and purposes (Van Eenbergen et al., 2017).

Due to a higher likelihood of encountering illness and chronic conditions, older adults have an increased demand for health-related information compared to younger individuals (Kovner et al., 2002). As the global population ages, a growing number of health-conscious older adults are actively seeking health information to make more informed decisions about their well-being (Medlock et al., 2015). The Internet offers the advantage of widespread accessibility (at home, work, and libraries), convenience (available 24 hours a day from home), and anonymity. Gathering more information from the Internet has the potential to enhance patients' comprehension of their medical condition and self-care (McMullan, 2006). Health information is increasingly accessible on the Internet due to the continuous expansion of medical websites. Although many are designed for healthcare professionals, an escalating number of websites are now directly catering to the general population, aiming to offer information about health issues, self-care, and preventive measures (Cline and Haynes,2001). Furthermore, online health support groups, offering both social support and information, provide participants with round-the-clock availability, the option of remaining anonymous, and exposure to a diverse range of opinions and expertise (Benigeri and Pluye, 2003).

The characteristics of patients have undergone a significant transformation in recent years. They are now more confident, dedicated, and inquisitive, not hesitating to inquire about their health status. Direct-to-consumer promotion (DTCP) has played a pivotal role in empowering patients. DTCP involves the direct promotion of pharmaceutical products to the patients themselves (Gu et al., 2011). As per a study conducted by (Page, 2018), 59% of patients favor searching for information on social media or the web as their main source. The research indicates variations in the frequency of use among different social media platforms. Interestingly, the study found that the extent of digital engagement was not correlated with the size of the firm. Furthermore, the majority of these firms aim their communication efforts toward the general public (Costa et al, 2018).

LITERATURE REVIEW

Technological advancements have led to a surge in the utilization of online patient support groups. Individuals now engage in discussions with fellow patients, physicians, and caregivers regarding their diseases and experiences through written communication, forums, and other online platforms (Pandey et al., 2021). Online patient support groups provide

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individuals, including patients, disease survivors, and caregivers, with a range of advantages, along with some drawbacks, when it comes to garnering social support for their health-related concerns. These groups are particularly valuable for those with rare health conditions or issues that may be challenging for doctors to fully comprehend or explain in simple terms. Additionally, individuals often turn to online patient support groups when members of their primary social network, such as friends and family, lack a deep understanding of their health condition (Pandey et al., 2022).

In recent times, researchers have begun exploring into the therapeutic processes that unfold within online support groups and the potential advantages they may offer to patients. The prevailing body of literature has predominantly centered on examining the dynamics of social support within these online communities (Blank et al., 2010; Coulson et al., 2007; Meier et al., 2007, Mo and Coulson, 2008) and have pinpointed the delivery of informational, emotional, and esteem support as the most prevalent forms within online support groups. Moreover, an expanding body of research has directed its attention towards investigating the potentially empowering effects associated with active participation in these online support communities (Bartlett and Coulson, 2011; Mo and Coulson, 2010; van Uden Kraan et al., 2008, 2009). According to these researchers, the social support dynamics within online support groups possess the capacity to empower patients. Online communities serve as significant platforms for individuals to seek health information and share their experiences with medical treatments. Online Health Communities (OHCs) facilitate the exchange of medical knowledge through various channels, including mailing lists, newsletters, message boards, blogs, discussion forums, and social networking sites. These communities play a crucial role in connecting patients with similar health conditions, enabling them to exchange insights and experiences related to treatments and nutritional regimens (Yan et al., 2016).

Experts have expressed apprehension regarding the marketing of pharmaceutical drugs directly to consumers on social media. This form of advertising, known as interactive direct-to-consumer advertising (DTCA), raises concerns because the unregulated nature of social media platforms may lead to an exaggeration of the advantages over the disadvantages (Tyrawski and DeAndrea, 2015). The population of individuals seeking information and reading about health experiences, whether their own or their loved ones', through social media is rapidly expanding. Pfizer stands out as having the most active social media presence on platforms like Facebook and Twitter (Liang and Mackey, 2011). Social media platforms such as GlaxoSmithKline's blogs and AstraZeneca's Facebook page specify that they are "intended for US residents/customers only," although there are no explicit restrictions for non-US users. Novartis, on the other hand, has developed a dedicated social media platform named CML Earth (Chronic Myelogenous Leukemia) specifically for patients dealing with leukemia (around the world). This platform enables patients to connect with one another, doctors, and online communities. According to experts, the use of Social Media Platforms (SMP) for pharmaceutical drugs has seen a significant increase, particularly during pandemics such as the COVID-19 outbreak (Chiplunkar et al., 2020).

METHODOLOGY

The mixed research design is used in the current study to investigate the Online Patient Support Groups. The mixed research design allowed for a comprehensive exploration of the phenomenon of Online Patient Support Groups. The Present study used qualitative method (netnographic observation that include thematic analysis). The study has been conducted in two ways:

Data has been collected manually

1. At the initial stage, we discovered 226 online patient support groups through manual web searches that are currently active globally.

2. We have visited all the 226 websites one by one and we find out that Information about disease, Diagnosis, Contact Support is provided in these Online Patient Support Groups.

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3. We have created few parameters which includes Awareness Campaigns, Contact detail provided, Diagnosis provided, with patient-physician interaction, with physician name, Information about adverse effect of medicine, with latest research, Information about medication cost, with medication instructions and medicine brand provided.

4. On the basis of this parameters all the 226 websites has been opened and searched one by one.

5. The result varies from one parameter to another.

Data has been collected through web scraping:

1. The first step involves extracting textual information from a website. This data extraction process, known as web scraping, utilizes software that can either access the World Wide Web directly through the Hypertext Transfer Protocol or use a web browser. It's important to note that web scraping should always be conducted in accordance with the terms and services of the website. Additionally, the extracted text may include HTML tags.'

2. During the second phase, it is necessary to cleanse and preprocess the text. Text preprocessing involves transforming the text into a format that is predictable and suitable for a particular task. Subsequently, HTML tags, punctuation, and stopwords (such as 'the,' 'and,' 'is,' etc.) have been eliminated from the text.

3. In the third step, we implemented a natural language processing approach. Firstly, we utilized 'BeautifulSoup' from the bs4 Python library for HTML parsing, creating a parse tree without eliminating stop words. This library is instrumental in parsing HTML and XML documents, enabling data extraction for web scraping purposes. Additionally, we used NLP libraries like NLTK and spaCy to recognize themes or sentiments, incorporating the removal of stop words in this process.

   NLP : Natural language processing stands at the intersection of computer science and linguistics, aiming to empower computers with the capability to understand and manipulate human language.

   NLTK : The Natural Language Toolkit, often abbreviated as NLTK, comprises a set of libraries and programs designed for symbolic and statistical natural language processing specifically for English. These resources are implemented in the Python programming language.

   spaCy : spaCy offers diverse linguistic annotations to provide a deeper understanding of a text's grammatical structure. This encompasses information about word types, such as parts of speech, and the relationships between words in the text.

4. In the fourth step, we manually established and redefines the themes.

5. In the last Step, we have interpreted the results.

RESULTS AND DISCUSSION

We have identified the top 10 groups out of 226 groups with a substantial number of active participants and this are also the most liked and followed groups. Diagnosis and contact details are provided on all the 10 online patient support groups while information about medicine is provided in 5 groups. Information about disease, symptoms, how to care are all provided in these groups.

Online Patient Support Groups	Like	Follow	Information about Medicine	Diagnosis	Contact details
Canadian CMTC Foundation	4221645	4215022	Not Provided	Provided	Provided

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ALS Association	908384	893099	Not Provided	Provided	Provided
Pancreatic Cancer Action Network	257338	243999	Provided	Provided	Provided
Cystic Fibrosis Foundation	232413	220744	Provided	Provided	Provided
Facial Pain Association	8626	86215	Provided	Provided	Provided
The Ehlers Danlos Society	79897	81389	Provided	Provided	Provided
The Guthy Jackson Charitable Foundation	42698	42734	Not Provided	Provided	Provided
Foundation Fighting Blindness	41459	41109	Not Provided	Provided	Provided
National Brain Tumor Society	38534	37932	Provided	Provided	Provided
Hydrocephalus Association	38652	37895	Not Provided	Provided	Provided

Table 1. Top 10 Online Patient Support Groups

Each of the parameters which includes Awareness Campaigns, Contact detail provided, Diagnosis provided, with patient-physician interaction, with physician name, Information about adverse effect of medicine, with latest research, Information about medication cost, with medication instructions and medicine brand provided have been searched on each of the websites. The results are shown in the graph below.

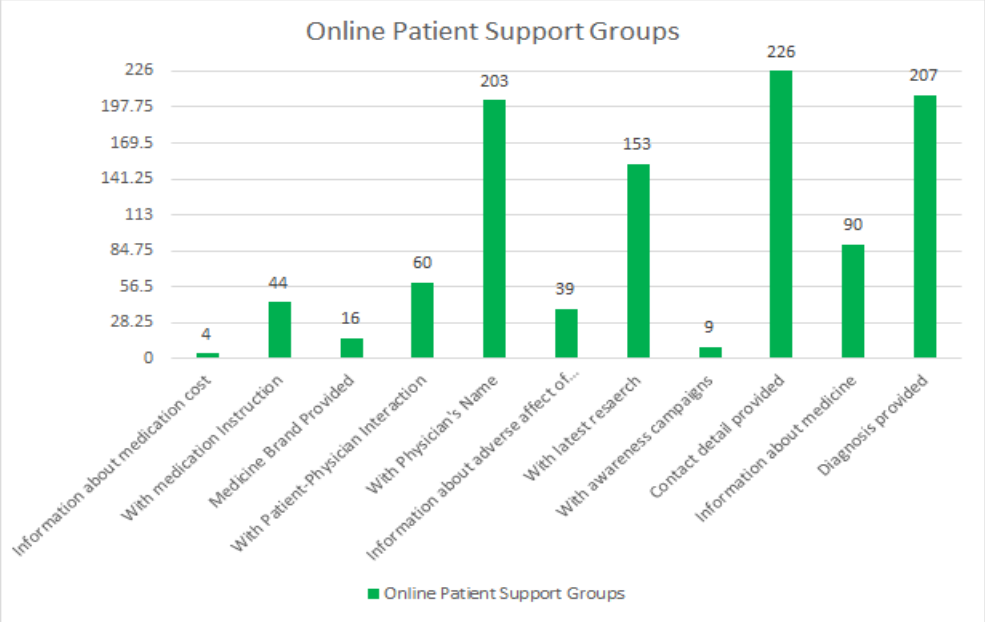

Figure 1: Details of Online Patient Support Groups

To find out some of the common words of the website we automated the processing and analysis of text, we represent the text in a format that can be understood by computers. spaCy helped us in doing that. The following words have been obtained from a single online patient support group known as the Acoustic Neuroma Association.

website: https://www.anausa.org/

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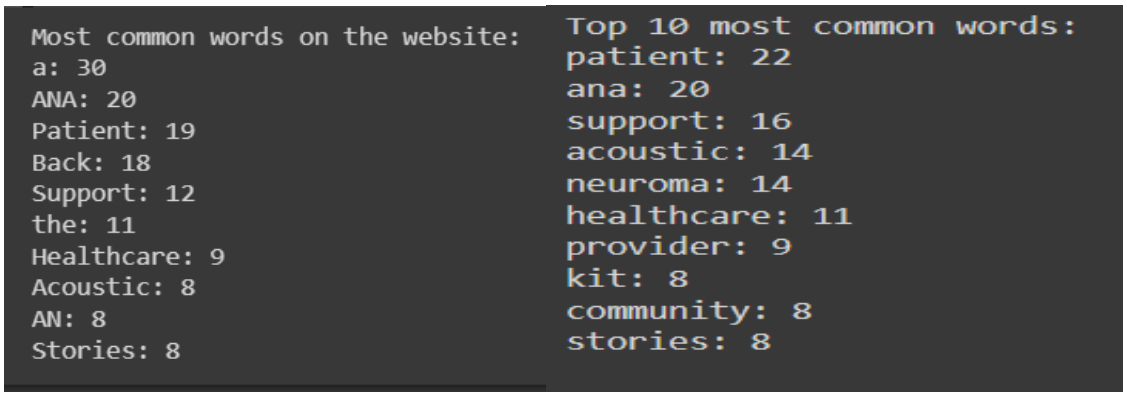

(a) Includes Stop Words (b) Removed stop words

Stop words: Stop words, found in a stop list (or stop list or negative dictionary), are eliminated (i.e., stopped) before or after the processing of natural language data (text) due to their lack of significance.

There are more other common words found from 226 online patient support groups (OPSGs).

Words	**No. of times words repeated. (Among OPSGs)**
Information	30
Patient	56
Help	23
Awareness	19
Learn	35
Community	34
Medical	32
Disease	35
Families	27
Contact	22
Care	27
Foundation	70

Table 2. Words repeated among OPSGs.

Online Patient Support Groups	**Words**
Canadian CMTC Foundation	Disease, families, rare, support, foundation, need, patients, caregivers, physician, treats, want.

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Table 3.

Phace Syndrome Community	Abnormalities, research, defects, brain, medical, anomalies, support, diagnosis, learn, rare, disease, advisory
RYR-1 Foundation	Family, diseases, care, clinical, research, patient, guidelines, help, fundraiser, support, resources, medical, impact, affected, provider.
TESS Research Foundation	Epilepsy, resources, foundation, care, cure, impact, donate, partners, join, diagnosed, learn, Patient.
Pancreatic Cancer Action Network	Cancer, research, contact, resources, learn, network, patient, treatment, stories, community, patients, story, support, clinical.
Cystic Fibrosis Foundation	Read, cystic, fibrosis, research, community, diagnosis, cure, search, therapy, learn, diagnosed, child, help, life, managing, news
Facial Pain Association	Pain, facial, support, find, learn, group, neuralgia, patients, education, virtual, emergency, donate, understanding, managing.
Acoustic Neuroma Association	Patient, support, healthcare, community, stories, association, events, library, volunteer, join, video, discussion, forum.
The Ehlers Danlos Society	Cookie, consent, user, store, youtube, category, information, plugin, session, visitors, analytics, joint
Foundation Fighting Blindness	Eye, research, news, blindness, fighting, cure, disease, retinal, events, education, learn, stories, vision, accessibility, genetic, testing

Different Keywords of Online Patient Support Groups

CONCLUSION

Online Patient Support groups haven an ultrafast growing phenomenon, ostensibly because these fulfil a critical need in healthcare. It is important to understand this phenomenon qualitatively and quantitatively. For qualitative study one important objective that has remained unfulfilled has been to undertake a content analysis of sample of these OPSGs. This paper has undertaken a content analysis manually as well as using netnographic approach using thematic analysis by computational extraction of textual information. The results have been presented in tables and graphs. It concludes that these are quite similar in the information these provide and may of the terminologies occur in them again and again. This shows that needs of patients are extremely similar and the regulatory bodies and healthcare providers must use these information to ensure sound OPSGs operate on net.

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