Communication and Interaction in Haemophilia-Centred Social Media Communities in Turkey

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Authors’ contributions

This work was carried out in collaboration between both authors. Both authors read and approved the final manuscript.

Article Information

DOI: 10.9734/JAMMR/2021/v33i1831071

Article Information

Received 20 June 2021
Accepted 24 August 2021
Published 03 September 2021

ABSTRACT

In rare diseases like haemophilia, access to information and experience as well as social and psychological support from social and scientific environments, especially from one’s peers and family, is important as the treatment itself. The development of social networks with the advance of communication technologies may provide health benefits for establishing and strengthening a support system. Focusing on communication and interaction in haemophilia-centred Facebook communities in Turkey, this study aims to analyse the roles and functions of such online communities in sharing and mitigating the health problems of haemophilic individuals and offering them social and psychological support. Accordingly, out of the 25 Facebook communities with Turkish content, all 10 active and open-access communities were included in the research sample and analysed through discourse analysis. The research discloses that there are discursive and functional differences in online communities established by individuals and institutions. Whereas the pages managed by organizations include more informative content with little interaction, the individual pages play a more affective role in the daily lives of haemophilic individuals, resulting in a strong network of solidarity. Therefore, the discourse on online communities were classified into two main categories, namely information exchange and emotional support. The current research
on Turkey reveals the role of online communities in haemophilic individuals’ access to information on haemophilia and its treatment as well as social and psychological support. Moreover, the current research also provides room for discussion on how these online communities can better contribute to solidarity between haemophilic individuals, families, and health professionals.

Keywords: Haemophilia; communication; social media; online community; Turkey.

1. INTRODUCTION

Haemophilia is a genetic disorder affecting 1 in 10,000 individuals, recessively inherited through the X chromosome. As in other rarely seen diseases, academic studies and policy regulations on haemophilia largely focus on medical treatment. The official haemophilia monitoring system in Turkey has been out of use since 2015. As of May 2015, there were 4,860 haemophilia A and 878 haemophilia B patients recorded [1]. Today, despite fast advancements in haemophilia care, arthropathy is the most common cause of morbidity in haemophilic individuals [2]. In the pathogenesis of haemophilic arthropathy, recurring hemorrhage lead to effusion in early stages, hemosiderin deposition, and synovial hypertrophy. In the chronic phase, destructive changes such as loss of cartilage, erosions of bone tissues, and development of subchondral cyst are observed. Psoriatic arthritis is mostly seen in knee, elbow, and ankle joints [3,4]. The permanent injuries in these joints have physical, psychological, and social impacts on the individuals’ lives. While the quantitative data provides a certain framework for medical treatment of haemophilia in Turkey and similar developing countries, there is still a limited number of qualitative and multidisciplinary studies that seek to understand, explicate, and improve the psychological and social conditions and daily struggles of individuals with haemophilia.

In rare and chronic disorders like haemophilia, the traditional communication channels that define face-to-face interactions with health professionals, associations, and NGOs are not only less effective, but also less practical given the technological advancements of our age. As in most chronic disorders, haemophilic individuals develop practical ways of accessing medical knowledge on their disorder as well as ways to combat the daily problems. In parallel with the development and proliferation of social networks, faster and effective ways of sharing information and experiences have become possible. [5-7] A cross-sectional research on adolescent patients in Turkey revealed that the participants spent 4.4 hours on the Internet every day and followed medical websites, news stories about haemophilia, and the web pages of non-governmental organizations working on haemophilia [8].

The communication and interaction on the online communities established on social media platforms are of special importance in partially overcoming the geographical, cultural, and economic limitations for the entire health communication processes and especially in rare diseases like haemophilia. This is why the current study focuses on how haemophilic individuals in Turkey use haemophilia-centred Facebook pages, and in particular how they make use of these communities with reference to psychological and sociological elements. This allows for a better understanding of the role of online communities on the lives of haemophilic individuals, which, by extension, provides the ground for a fertile discussion on how these online communities can be used to increase the living standards of patients. Therefore, the current study also aims to facilitate global, local, or regional actions.

2. METHODS

As the social network with the largest target audience, and due to its intrinsic function as a place for information sharing and gathering, Facebook has been identified as the research field. According to “We are social” digital report 2020, Facebook is the most widely used social media platform with 2,449 million active monthly users. With 37,000,000 users, Turkey ranks 10th around the globe with highest number of Facebook users [9].

A search on Facebook using the keyword “hemofili” (Turkish for ‘haemophilia’) returns 25 online communities. While 20 of these online communities are Facebook Pages, 5 were established as Facebook Groups. Pages are places where artists, celebrities, enterprises, brands, institutions, and non-profit organizations can reach out to their fans or customers. When a user likes or follows a page on Facebook, the
user starts receiving the updates of the pages in their news feed. The Groups, on the other hand, are places where users sharing the same interests can communicate. Users can establish a Facebook Group for any type of gathering, event, or subject. It is also possible to adjust privacy settings to define who can join the group or view its content. Once a user joins a Facebook Group, the user starts receiving updates from the group in their news feed.

In this way, all active (which refers to at least one content share in the past year) and open-access groups and pages have been included in the research sample. There are 9 such pages and 1 Facebook Group (See Table 1).

The current research, which embraces a multidisciplinary approach, analysed these online communities through discourses analysis to find out their roles in sharing and mitigating the health problems of haemophilic individuals and offering them social and psychological support.

Simply put, discourse refers to an analysis of the language. However, this analysis moves beyond the syntactic and semantic limits of the expressions in each text and requires exploration of their meanings and content. As such, discourse analysis does not limit itself with the formal aspects of language use and encompasses the social incidents occurring between the language users who communicate in a certain social and cultural context [10]. An oft-used method in social sciences, and especially in communication sciences, discourse analysis enables definition and interpretation of the use of language as well as reproduction and transformation of relations and representations in media texts depending on social conditions and the ways in which language is processed under these conditions.

Offering hints for understanding the ways individuals shape their world and make sense of their daily lives, discourse analysis is a useful methodology for the current study as it constructs society and culture and enables explanation and interpretation of the links between text and society [11]. All of the shared content, posts, and comments on the 10 Facebook communities that form the research sample of the current study were analysed through discourse analysis. This allowed a discursive definition of the contexts of discourse and expressions of groups, relations, struggles, opinions, prejudices, assumptions, implications, and ideas. During the analysis, besides the texts and/or images, the tone of the language that used, the authority to post on pages, the context and scope of communities, expressions (including the emojis) are considered as in relation to both each other and culture that they are part of.

Accordingly, the analysis of the findings focused on how discourse is constructed and reproduced as well as how texts do or do not appear in these communities with reference to their contexts. This entailed an analysis of not only “what is said”, but also “what is meant” through implications and presuppositions.

3. RESULTS AND DISCUSSION

There are three main actors in haemophilia communication based on the analysis of online communities and similar prior work in literature. [12-14] The first of these actors is, naturally, the haemophilic individuals themselves. The most important function of communication and interaction on online communities such as Facebook groups is that they enable haemophilic individuals to communicate with one another. This makes it possible for haemophilic individuals to share experiences and learn from each other.

The second fundamental actor is the “caregiver”. Starting from very young ages, parents perform an important role in providing information, care, and support haemophilic individuals need for a quality and self-sufficient living experience together with treatment methods that can be applied at home. Therefore, parents and immediate acquaintances play an active role in haemophilia communication to cope with the emotional burden of care work and to be able to educate the haemophilic child for self-care in later stages of their lives.

The third actor with an active role in the process is the health professionals and the non-governmental organizations or associations where these health professionals are performing actively. A patient’s relation with health professionals is important for continuation of monitoring and treatment, exchanging information in a safe environment, and satisfying needs for accessibility in urgent cases. [15] In this sense, the way communication and interaction unfold on online communities such as Facebook groups functions as an alternative medium for haemophilic individuals to keep up with latest news stories, access to information and news sources, and contact experts, especially health professionals.
Table 1. Research sample

<table>
<thead>
<tr>
<th>Type of community</th>
<th>Managed by</th>
<th>Post authorization</th>
<th>Follower/member</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group</td>
<td>Individual</td>
<td>Anybody</td>
<td>1.032 member</td>
</tr>
<tr>
<td>Page</td>
<td>Individual</td>
<td>Anybody</td>
<td>121 follower</td>
</tr>
<tr>
<td>Page</td>
<td>Individual</td>
<td>Anybody</td>
<td>420 follower</td>
</tr>
<tr>
<td>Page</td>
<td>Individual</td>
<td>Admin</td>
<td>5.629 follower</td>
</tr>
<tr>
<td>Page</td>
<td>Organization</td>
<td>Anybody</td>
<td>2.806 follower</td>
</tr>
<tr>
<td>Page</td>
<td>Organization</td>
<td>Anybody</td>
<td>1.116 follower</td>
</tr>
<tr>
<td>Page</td>
<td>Organization</td>
<td>Admin</td>
<td>982 follower</td>
</tr>
<tr>
<td>Page</td>
<td>Organization</td>
<td>Anybody</td>
<td>515 follower</td>
</tr>
<tr>
<td>Page</td>
<td>Organization</td>
<td>Admin</td>
<td>340 follower</td>
</tr>
<tr>
<td>Page</td>
<td>Organization</td>
<td>Anybody</td>
<td>331 follower</td>
</tr>
</tbody>
</table>

The research also reiterated the significant role of associations and federations in such groups in as much as the 6 online communities out of the 10 included in the current research are run by associations, federations, and other non-governmental organizations. This signifies how NGOs increase the use of social media platforms and digital communication. Congresses, summer schools, workshops, and regional meetings, which are at the forefront of activities undertaken by these organisations, bring together health professionals and patients. In addition to transfer of theoretical knowledge, such gatherings also enable direct communication between patients and health professionals. They also allow patients to exchange experiences in relation to their problems and solutions. Since 2020, the NGOs continue these organizations online in response to the COVID-19 pandemic.

The research findings indicate the online communities run by organizations (NGOs) are more informative with relatively little interaction. On the other hand, online communities established by individuals tend to play a bigger affective role in the daily lives of haemophilic individuals, resulting in much stronger networks of solidarity. The communication and interaction on the Facebook groups can be classified into two main categories: information exchange and emotional support.

3.1 Information Exchange

Among the problems haemophilic individuals face in their daily lives are impacts on mobility due to limited joint movement, vascular problems resulting from intravenous treatment, setbacks in treatment due to antibodies developed in response to concentrated factors and subsequent lack of compliance with medication [8,16]. These problems are also reflected in the posts of haemophilic individuals on online communities analysed herein. These physical problems are coupled with psychological and social problems. A study comparing 40 haemophilic children with their health peers indicated depressiveness and lack of self-confidence [17]. These physical and psychosocial problems affecting the living standards and perception of health [18] are also reflected in the posts in online communities.

Information exchange refers to contents such as news stories, event announcements, and transfer of scientific knowledge with a focus on haemophilia, including information on the problems faced by haemophilic individuals, caregivers, and non-governmental organizations. These contents mostly relate to treatment and access to medication. Haemophilia care, which witnessed notable improvements with new medication and approaches, has an important part in the organization of health systems in different countries, partially due to the impact of its cost. Therefore, it is important for haemophilic individuals and their caregivers to follow the latest local and global health news. Currently, access to such news stories is made possible through social media, consultation of health professionals, and taking part in trainings organized by NGOs.

Posts on online communities focusing on treatment and medication enable the members to inform one another about access to treatment and medication in line with the latest news stories and practices. Also, health professionals occasionally respond to the questions of haemophilic individuals and their families. The ability of online communities to provide for such an interaction between health professionals and patients/families point to an important role in the sense of dissemination of genuine information and spontaneous and fast contact with health professionals. Spatial and temporal obstacles on
access to information may be circumvented through online communities.

News stories and announcements of events are also classified as part of information exchange. Posts on news stories and events consist of formal and informal meetings and consultations, latest news stories, and announcement of events on haemophilia such as congresses, conferences, summer schools, and webinars. Doctors and nurses working on haemophilia, haemophilic individuals and their families come together in the regular scientific events and meetings. Therefore, such events play a vital part in forming a strong haemophilia community, both online and offline. The strong connection established between the three actors defined above is also reflected in communication in online communities. To illustrate, users tag a person (for instance a haemophilic journalist) believed to have the most recent and correct information about a new story or discussion in the group. Similarly, the page admin directly intervenes to respond to complaints or recommendations on the activities of an NGO. To conclude, the analysed online communities allow for a non-hierarchical communication model (through eliminating bureaucracy) and strengthen the communication and interaction between actors thanks to their recognition and reputation.

3.2 Emotional Support

In addition to providing a platform for sharing information and news stories, online communities also play an indispensable role in offering emotional support. Scientific publications and data sharing in scientific meetings are the fundamental sites for know-how exchange for scientists and health professionals. While such platforms and exchanges thereof are critical for scientific knowledge and progress, exchanges on online communities are equally essential for providing social and psychological support to patients and families.

These groups are places where haemophilic individuals and their families frequently share their experiences. Such posts provide feedbacks based on prior experience rather than information of the treatment process itself. As such, they allow for experiential learning. More importantly, communication and interaction in the communities provide not only information, but also emotional support for haemophilic individuals, and especially those with more recent diagnosis. In this sense, such groups welcome the haemophilic individuals and their families with an inclusive discourse as “we are a family” and therefore offers a sense of solidarity that goes beyond the borders of online platforms. User posts in such groups include the likes of “Hello there. I am new as well. I am haemophilic yet I am a child”, to which another member responded as follows: “No worries, my dear. My daughter is a little child, too. She was diagnosed when she was 3. You will be stronger with the support of your family”. Another user commented on the same post: “No need to be afraid. I was diagnosed when I was six months old. Now I am 29. Everything is going to be alright with a healthy and protective care. There has been great progress over time. Stay healthy!”.

As shown in the examples above, coming together in an online community of children and adults and being welcome with a warm “I am here, too” or a “hello” may help haemophilic individuals and their families to better cope with loneliness, marginalization, concern for a lack of empathy. It is important to note that this emotional connection and support is not limited to patients and their families. The fact that the most revered and leading health professionals in the field are associated with love, gratitude, and companionship indicate that patients and families form strong emotional bonds with these leading figures as well.

Haemophilia-centred Facebook communities satisfy the need for belonging in a community, a function that is often not observed to this extent in digital platforms. As such, online communities provide a platform for individuals to discuss, exchange opinions, and express their ideas in an environment where they can raise their voices and share their experiences and emotions.

4. CONCLUSION

There are contradictions whether social media is liberating, emancipatory, or controlling in a local scale. Yet, in this research and this specific case, we may argue that social media platforms like Facebook create more space for self-presentation and privacy and new opportunities for participating in a new public life, communicating with people who share similar experiences. In other words, social media make what is publicly invisible, visible.

The analysed haemophilia-centred Facebook communities enable information exchange and
communication between the three main actors of haemophilia communication. Results show the significance of associations and federations, depend on bringing together the main actors, although for some of the communities the interactivity needs to be increased. Also online communities’ role in strengthen the solidarity among those actors and creating space for experiential learning, are also part of striking findings. The current study shows that Facebook communities perform a largely irreplaceable function as a platform for information exchange on useful information and news stories as well as for providing emotional support for individuals with this rare disorder.

On the one hand, it is important to provide various opportunities for transfer of knowledge and experience about haemophilia, its treatment, and the lives of haemophilic individuals in addition to access to medical treatment in Turkey. On the other hand, the role of certain opinion leaders who are not health professionals also bring about the risk for dissemination of false information. In Turkey, 63% of adults aged 18+ declared that they are concerned about what is real or fake on the Internet. Concerns about misinformation and fake news rate in Turkey is above worldwide average of 56%. Therefore, a well-informed organization of online community management is much needed.

This research is expected to contribute to the literature on haemophilia in developing countries like Turkey, to support qualitative and multidisciplinary endeavours, and to inspire similar approaches and comparative analyses.

DISCLAIMER

There is absolutely no conflict of interest between the authors. No company was involved in this study neither the study was funded by the company.

CONSENT

Not applicable.

ETHICAL APPROVAL

Not applicable.

ACKNOWLEDGMENTS

Serra Sezgin designed and performed the research. Also, she analysed the data and wrote the paper. Mehmet Can Ugur contributed essential reagents or tools.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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