

Chapter 22

How Is the Administrator's Experience in Managing Health Facebook Groups?

The Impact of Social Media in Patients With IBD

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ABSTRACT

This decade, patients with chronic conditions take advantage of technological resources to share experiences, look for help, and get together in groups. Social media has become a productive spot of health information for users. This chapter clarifies the administrators' user experience of social media health groups within the context of the Inflammatory Bowel Disease (IBD). Semi-structured interviews with 7 Portuguese and Brazilian managers of Facebook groups were carried out. The authors propose a model of participation in online communities that take into account the variables of Presence–Interconnection between users in daily lives; Relationship–Aspects of experience where users meet; Reputation–Positioning of users related to the status; Groups–Relationship issues between members; Conversations – Extension of the user interaction; Sharing–Represents the exchange, distribution, and reception and Education–The information transmitted. Findings reinforced that administrators' groups use social media to lead patients' empowerment.

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INTRODUCTION

Social media, as a phenomenon of the current decade, assemble a group of digital tools under a single term. The use of these media is permeated by the ideology of contribution, in which users take advantage of technological resources not only for sharing, but also to create content (Kaplan, 2013). As a consequence of the factors pointed out, citizens with different goals are using different media while interacting with a multitude of content and people, forming groups, communicating and increasing their network. In some cases, coming together for a common purpose. In fact, it is interesting to recognize that the health topic is actively used with digital media since the beginning of the current decade.

Relative to this fact, a study (Fox & Duggan, 2013) revealed that 72% of Internet users looked for information on the experience of others with the same type of health problems, and 8% posted this type of content. In the same period, Hartley argued (2012) that communication about health in the digital context was a critical issue because citizens were simultaneously positioned as both patients and 'active' participants in healthcare (Erikainen, Pickersgill, Cunningham-Burley, & Chan, 2019).

The profile of participants mentioned before is what some authors (Guo, Reich, Groshek, & Far-raye, 2016) announced as 'e-patients.' The term was coined to describe those who are looking for health information in the online environment. They also warned, in their study, that adults were using social media networks to improve their knowledge in this particular field. This means that not only patients were connecting with disease communities but, they were accessing to these and being co-producers of knowledge and information with a linguistic level that can be perceived by most of the patients. Regarding the conception of these communities, they are driven by support and a follow-up of other patients during treatments (Frohlich, 2016; Guo et al., 2016; Reich et al., 2019).

Studies have shown that participation in this type of groups had improved patients' quality of life through sharing experiences with others, and families, promoting the socialization and clinical orientation which means, they, likewise, are also exchanging information about new medical treatments (Szeto et al., 2018). These communities have substantially grown, and about this phenomenon, a different paradigm has emerged, i.e. patients whose quality of life depends on several healthcare services are exploring the advantages of social media to have feedback in real-time. They are also using these tools to help them managing their disease condition (Patel, Chang, Greysen, & Chopra, 2015; Taft & Keefer, 2016).

Social media as tools for disease management in chronic illnesses such as asthma, diabetes and cardiac diseases have been observed before (e.g. Ferguson et al., 2014; Hawn, 2009; Nickels & Dimov, 2012). Regarding patients with Inflammatory Bowel Disease (IBD), they are often using these tools to discuss their disease with peers, obtain educational disease-related information, and communicate with their physicians and patient-related organizations (Frohlich, 2016; Guo et al., 2016; Patel et al., 2015; Reich et al., 2019; Szeto et al., 2018; Taft & Keefer, 2016). The Facebook platform, as a social media tool, has empowered patients with chronic conditions expanding new ways of achieving knowledge, leading discussions, or promoting causes.

Beyond some intangible benefits of this involvement, there are significant tangible profits to the increased use of digital communication by IBD patients. These include low-cost access to crucial information about the disease, new ways of interacting with the community – build relationships, additional opportunities and sources to understand who the healthcare providers of specific customer services are (Carroll & Ramachandran, 2014).

After an introduction elucidating about the context of this chapter, in the following sections a clinical summary about IBD and the evolution of IBD health information in the digital world will be introduced.

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