

Examination of weak tie network theory in ulcerative Colitis and Crohn's online communities / Shimrit Zigron

Abstract

Chronic diseases such as kidney disease, cardiovascular diseases, cancer, chronic respiratory diseases, and diabetes are a healthcare concern worldwide. These diseases increase the mortality rates worldwide, and there is a systematic growth in children, adolescents and adults who suffer from them. Chronic diseases require constant care, and changes in a person's lifestyle such as smoking cessation, dietary changes and regular exercise in order to enable a normal lifestyle alongside the disease. Studies confirm that patients suffering from chronic disease and their caregivers are highly engaged in the pursuit of health information, support and advice, both online and offline.

In the last decade, the rapid growth of Internet access and computer-mediated communication (CMC) has created new possibilities for people with health-related concerns to engage in supportive communication with individuals coping with similar problems that would be difficult or impossible to form in the face-to-face world. While face-to-face support groups continue to be popular among people facing a variety of health issues, there are a number of unique communication characteristics that have been observed within health-related computer-mediated support groups. These characteristics include: (a) the ability of computer-mediated communication to transcend geographical and temporal constraints; (b) the opportunity for people to disclose health information with less risk than in face-to-face contexts; (c) greater access to diverse sources of health information than are typically available in face-to-face contexts; (d) the facilitation of more heterogeneous supportive relationships due to reduced social characteristics in the computer-mediated environment.

Many of the findings from empirical studies of computer-mediated support groups can be linked to the "Weak Tie' Networks" theory. "The Strength of Weak Ties" is the most famous work of the sociologist Mark Granovetter, which was published in 1973

and won him many awards. His work examines processes of distributing information between humans at the interpersonal level.

According to Granovetter, each person has a collection of close friends, most of whom are in touch with one another that result in a densely knit clump of social structure. In addition, each person has a collection of acquaintances, few of whom know one another. Each of these acquaintances, however, is likely to have close friends of his own. The weak tie between a person and his acquaintance, therefore, becomes not merely a trivial acquaintance tie but rather a crucial bridge between the densely knit clumps of close friends. It follows, then, that individuals with few weak ties will be deprived of information from distant parts of the social system and will be confined to the provincial news and views of their close friends. This deprivation will not only insulate them from the latest ideas and fashions but may put them in a disadvantaged position in the labor market, where advancement can depend on knowing about appropriate job openings at just the right time. (Granovetter, 1973, 1983)

‘Weak tie’ relationships typically take place between individuals who communicate on a daily basis, but are not necessarily close. Prior to the Internet, weak tie networks for most people consisted of neighbors, service providers and other individuals a person could turn to during times of stress when closer ties (e.g. friends and family members) were unavailable. The Internet has greatly expanded the number of relationships that could potentially become weak tie support networks for people with health concerns. For example, using online health communities, online health forums, online chat rooms, listservers and bulletin boards. All of these media provide a framework for information exchange and support without prior acquaintance with other users.

The purpose of this study is to examine the "Weak Tie Networks" theory in a new research field: online health community for Ulcerative Colitis and Crohn's patients. Crohn's disease is a chronic inflammatory disease of the digestive system which afflicts mainly in the intestines but can affect any tissue in the digestive tract from the

mouth to the anus. The disease tends to occur equally in men and women, especially in youth. (Between the ages of 15-30). The disease tends to get chronic nature with flare-ups (expressed in stomach pains, diarrhea and bleeding) and remissions. Until today the cause remains unknown and the treatment is focused on suppressing the inflammation and the immune system.

In recent years, there is a significant increase in the number of online health communities for Ulcerative Colitis and Crohn's patients, however the researcher was unable to find studies on the role of these communities for these patients. Only in the United States, there are hundreds of online health communities for Ulcerative Colitis and Crohn's patients. Moreover, there is a trend mainly in the U.S and Europe (with an emphasis on United Kingdom) to create online health communities and entire websites designed solely for teens and children who diagnosed with Crohn's disease. Hence, the questions this study asked were: what are the needs of these patients? Can we implement the "weak tie networks" theory on these online communities?

In order to examine these questions the researcher chose an online health community for Ulcerative Colitis and Crohn's patients in Israel, which included 1875 members as a research environment. The study consisted of two stages. The first stage included semi structured interviews with 23 Ulcerative Colitis and Crohn's patients, all of whom are registered members of the community. The interviews dealt with several of characteristics of "Weak Tie Networks" theory such as: overcoming time and geographic barriers, access to diverse information and the ability to disclose personal information due to reduced fear from stigma or rejection. The second stage of the study consisted of the content analysis of 262 posts that were published from August to September 2015 in the Israeli Ulcerative Colitis and Crohn's online health community. The data collected from the interviews and the content analysis of the posts were analyzed based on the "Weak Tie Networks" theory as well as the thematic analysis that revealed the subjects appearing in the data.

The findings of this study confirm some of the elements of the "Weak Tie Networks" theory such as: availability 24/7 of the online community, overcoming time and geographic obstacles, especially in patients who suffer from flare-ups and confined to their homes, access to diverse sources of information and ability to disclose personal

information due to reduced fear from stigma or rejection which is inherent in patients suffering from Ulcerative Colitis and Crohn's disease. In addition, the online community offers limited exposure. A person who is not a registered member in the community cannot see the posts which is being published in this community.

The findings have raised two elements in the behavior of these patients that are not part of the theory, but play a pivotal role in the decision of Ulcerative Colitis and Crohn's patients to join the online community. The behavior of members of this community is characterized by a sense of belonging and the desire of patients to compare their medical condition to other patients as a way to receive encouragement and motivation. The desire of these patients to feel a part of a group and to receive empathy from other patients, who understand what they are going through is one of the most important reasons for joining the online community. Many patients noted during the interviews that the nature of Crohn's disease is very isolating. (Due to the need to be near a toilet or in long-term hospitalization) and the online community often serves as a social framework when other social frameworks are not available. In addition, the desire of these patients to compare their medical situation with other patients as a way to receive encouragement and motivation is another reason for joining the online community. About a quarter of the interviewees indicated that reading about severe cases gives them encouragement and motivation to pursue therapeutic procedures despite the uncertainty.

In sum, findings from the study show that the "Weak Tie Networks" theory is partially relevant to the behavior of members of the online community for Ulcerative Colitis and Crohn's patients partially. The online community available 24/7 hours a day, including weekends and nights and allows its members to receive a quick response. The patients are exposed to diverse sources of information due to the large number of members in this online community (1875 members). This study also found that what is particularly important for Crohn's patients is information based on experience. The desire to find patients who had similar experiences outweigh the desire to receive information from various studies whether academic or medical or even from medical sites such as: WebMed. Finally, the online community allows the

patients to disclose personal information without the fear from stigma or rejection since all of its members suffer from the same medical condition.

This study also revealed the desire to belong and the desire to compare the medical situation with other patients as a way to receive encouragement. These two characteristics were not a part of "weak tie networks" theory, but they are an important reasons for joining and staying in the online community over time.

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