

# **Communication Privacy Management Process (CPM Theory) in Medical Support Groups on Facebook / Carmel Avizohar**

## **Abstract**

Facebook is a popular social network for medical support groups that allows conversations with people in similar medical conditions at any time and without geographical limitations. The purpose of medical support groups is to support and treat its members through social interaction characterized by request, information sharing, opinions and suggestions. They usually do not provide structured and professional treatment, but serve as a platform for sharing feelings and thoughts. The membership in these groups provides sophisticated ways of gathering information, and allows learning from others' experiences.

People who need medical care, for them or for relatives, spend time searching for information at various points in the course of the disease, achieving goals such as self-management, independence, improving self-esteem and managing a "normal" life, to avoid complications and improve chances of survival. Social media in general and Facebook in particular, have caused many not to rely on information provided passively, and want to be part of a dynamic information production process by offering solutions to problems, comments and sharing personal experiences. Discussions in Facebook's medical support groups challenge members to rethink and evaluate previous decisions, attitudes, and techniques to address emotional, social, and practical difficulties. The exchange of information allows members to leverage the collective wisdom of groups in their favor, learn firsthand about treatment methods and experts in a specific medical field, and obtain relevant information for making informed decisions.

Although health is a sensitive, personal and private matter, members of medical support groups reveal intimate details of daily life as a strategy for obtaining information. Uncertainty, coping and stress are prominent phenomena in medical information behavior, resulting in the fact that medical support groups are different from other Facebook groups. Despite the many benefits that come with joining support groups, members sometimes fear that exposing private medical information

will harm their social status, image and employment opportunities, and be abused by group members, admins or third parties such as insurance companies. Sometimes seemingly innocent information (e.g. geographic location, photos and life events) shared with people you trust can threaten privacy if distributed without consent.

Members of medical support groups have collective control over private information published in them, meaning that there is a group responsibility for the information published by each member. Therefore, there is a shared responsibility for the management of the private information of each of the members. Sharing sensitive experiences in a public discussion may cause a sense of loss of control over self-disclosure, and lead to regulation of behavior in sharing private information. Thus, medical support groups that provide a sense of trust and confidence, enable deep self-disclosure. Because confidentiality and privacy are the basis for mutual help and support, there is a need to understand ethics and privacy, and for the consent of members to disclose and use information out of free will and understanding of the consequences.

The present study was based on the CPM theory (Communication Privacy Management Process), which focuses on the process of managing private information, and was developed by Professor Sandra Petronio. The theory assumes that the process of disclosing private information is dialectical, meaning that people choose to disclose or hide information based on criteria and conditions they perceive as important, and believe in their right to hold and regulate the environment's access to their private information. CPM theory was chosen because it deals with the decision-making process related to private information, as appropriate for sensitive information that most owners are undecided whether to disclose in order to receive support or keep to protect their privacy (e.g. medical, mental or social information). The study examined the conditions that guide members of medical support groups on Facebook to disclose private information, and for this purpose, three research questions were selected:

- Is there a difference between men and women in terms of privacy, perception of support and engagement in Facebook group where they belong?
- Is there a difference between members of medical support groups and members of neutral groups in terms of privacy and support perceptions?
- What are the factors that explain self-disclosure in medical support groups on Facebook?

In order to answer the research questions, a questionnaire was written with reference to the five basic assumptions of CPM theory, based on four reliable questionnaires: a demographic questionnaire, a network activity questionnaire, a support questionnaire, and a privacy questionnaire. The questionnaire was distributed on Facebook in medical support groups and neutral groups that agreed to participate in the study and allowed their members to respond voluntarily. The answers of each group were collected in a Google Forms file, consolidated into an Excel file and analyzed statistically using SPSS software.

The sample included 293 participants, of whom 234 were women (79.9%) and 59 men (20.1%), aged 18 to 85 years. 80 of the participants have a high school education (27.3%), 35 of the participants have a bachelor's degree (46.1%) and 78 of the participants have a master's degree (26.6%). Two different study groups were sampled: one group included 155 participants (52.9%) members of Facebook medical support groups (experimental group, 103 women and 35 men), and a second group included 138 participants (47.1%), members of neutral Facebook groups (control group, 131 women and 24 men).

The findings of the study show that the level of support among members of medical support groups is significantly higher than the level of support among members of neutral groups. Privacy Indices "Privacy Policy", "Privacy Value" and "Self-Disclosure" are higher among members of medical support groups compared to members of neutral groups, among all the privacy indices surveyed ("Privacy Awareness", "Privacy Social Norms", "Privacy Policy", "Privacy Control", "Privacy Value", "Privacy Concern" and "Self-Disclosure"). The study shows that members of medical support groups attach greater importance to privacy policy, give greater value to privacy and reveal more private information, compare to people who are members of neutral groups.

It was found that the level of engagement (active participation) in groups among women did not differ significantly from the level of engagement among men, and that in general the level of engagement among members of medical support groups did not differ significantly from the level of engagement among members in neutral groups. Nonetheless, a high level of engagement will predict higher self-disclosure in medical support groups, so the more engage the group members are, the more likely they are to reveal private information.

According to the findings of the study, it is possible to predict the level of self-disclosure on Facebook groups, both in medical support groups and in neutral groups. The more support a

member feels from the group, the greater the level of this member's engagement in the groups' activities and the more he/she feels that the privacy is protected within the group's privacy policy - the more the member tends to disclose private information. The variables "level of support" and "privacy policy" mediate the relationship between belonging to research groups and the level of disclosure of information. That is to say, members of medical support groups tend to feel that they receive more support and feel that the privacy policy preserves their privacy much more. These feelings are associated with greater self-disclosure of groups' members.

Consistent with CPM theory, the study shows that in medical support groups on Facebook there is a high level of dialectic privacy management: members experience a need for self-disclosure, sharing and discussion of their personal situation, and yet feel the need to preserve and protect their private information. Human beings need a private space, a place where they can feel safe, be able to think, wonder, express themselves and make contact with others while feeling trust in them. It is in the power of medical support groups to provide a "safe haven" - a platform where members are not criticized but listened to, empathized and defended their right to privacy. Social expectations affect the perception of what is private information and what is public information, and they vary depending on the situation. Thus, group members have a great deal of influence on the management of the information published in them, and the desire for privacy in a public environment is not a logical contradiction - people can manage their privacy while sharing information on social media.

The study shows that the privacy policy is important for the members of the medical support groups and is a key consideration in the decision to disclose private information. Its enforcement will not only encourage self-disclosure in Facebook groups, but will also significantly reduce potential dangers involved in sharing information. The research insights will help Facebook groups members in general, and medical support groups members in particular, to put into action the fundamental right to privacy and build a set of rules tailored to their individual and group needs, and help groups form a private space where they will feel confident revealing private information within the privacy boundaries they feel are appropriate.

The findings of the study will help neutral group admins encourage privacy and strengthen members' sense of support, and to medical support group admins in choosing a privacy information

and knowledge management strategy and tailoring it to the group and members' goals in a way that encourages quality and supportive participation while maintaining privacy.

This research contributes significantly to members of medical support groups on Facebook and to its admins, but at the same time has some limitations. The data was collected using online questionnaire published in neutral groups and medical support groups answered voluntarily, with significantly more women filling out the questionnaires than men. A second limitation is the quantitative research method used for this study. The research set-up is horizontal and not longitudinal (that makes it possible to determine the causality of the relationships between the variables). Another limitation is the large number of medical support groups on Facebook that participated in the study, as there is no representative sample from each group on its own. However, this limitation is also the strength of the study - the sample presents for the first time a broad and deep picture of medical support groups in Israel, and proves how relevant online support and privacy are to a variety of medical conditions.

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