

Scientific Study

The Intent of Support Group Owners

Online support groups are a wonderful way to connect with others who are going through, or have gone through, similar struggles with an illness. They can answer questions, address concerns, provide encouragement, share tips and referrals, discuss treatments, and be there to understand and accept the illness reality when it seems no one else will.

Most support groups are very friendly and helpful. Occasionally a group may experience conflict and strife or suffer with a webmaster or moderator who seems to have a personal agenda. Researcher Van Uden-Kraan and colleagues expressed an interest in the motives and goals of people who facilitate these groups.

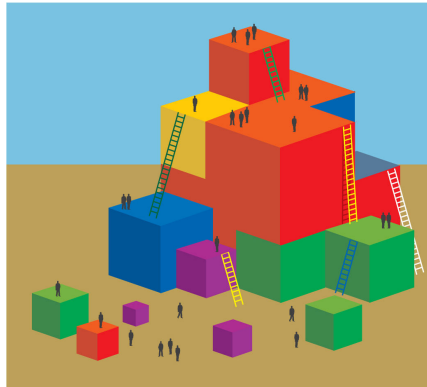
They interviewed groups for breast cancer, fibromyalgia, and arthritis. Most facilitators of the groups were women who also suffered with the disease.

“Analysis of the interviews revealed that webmasters had altruistic and intrinsic motives for initiating an online support group,” said Van Uden-Kraan in his published study. “They defined success as the fulfillment of the goals they had in mind when they initiated their groups. To be able to make a group successful, decisions about its organization and management need to be coherent with these goals.”

Facilitating a support groups takes quite a bit of time and energy, an average of 10-15 hours a week according to Van Uden-Kraan. “Management of the OSGs (online support

groups) took up much of the webmasters' time and energy.”

Moderated posts are often a conflicted subject among members. Some welcome moderation to keep the group on topic, while others feel that their opinions will be unfairly suppressed.



While it is extra work and not always well received, moderation ensures that the group stays on topic and prevents infighting. “Most webmasters stressed that promoting the group, keeping it alive and moderating the messages were vital success factors,” Van

Uden-Kraan reveals in the study.

Some group members are seeking help and support for a new diagnosis, while others are veterans who remain for altruistic reasons to support others long after they have been treated and stabilized. The veterans, like the facilitator, put significant time and energy into reading and responding to group messages. Some may even go on to do research or become activists.

It takes a special person who is willing to give back to the community by facilitating an online support group. There are many wonderful groups which have been a huge help to others who are struggling with a chronic illness. Kudos to them all!

Reference

Van Uden-Kraan CF, Drossaert CH, Taal E, Seydel ER, Van De Laar. Patient-initiated online support groups: motives for initiation, extent of success and success factors. *J Telemed Telecare*. 2010;16(1):30-4.