

Chapter 16

“There’s Always Hope:” Content, Participants, and Dynamics of Discussions in a Lung Cancer Internet Support Group

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EXECUTIVE SUMMARY

The Internet has changed the ways in which many people cope with illnesses, by allowing for conversations between similar others that transcend traditional barriers of time and place. Despite the revolutionary potential of Internet support groups, little is known about the ebb and flow of discussion in these groups. This chapter describes online discussion in a Lung Cancer Internet Support Group. Methods include quantitative and qualitative analysis of email messages posted to this group during one month. The results reveal (a) the content of the discussion, (b) participants in the discussion, (c) topics that elicited discussion and (d) themes and messages that were “silenced.” The implications of these findings to patients and their family members, to scholars, and to health practitioners are discussed.

INTRODUCTION

[last month] I joined this virtual family. After intro, I requested the experience of people as to what if anything to do next after successful sleeve lobectomy on right lung. The overwhelming response was to do something beyond just close monitoring. I am to begin some empirical chemo treatments...I am thankful for your pushing me to do something. Also I find that I am hooked to reading the [list's] mail

every day. Let us keep up the good work Gratefully in His Hands, Charles.^a

The above Email message of an elderly cancer patient to a Lung Cancer Internet Support Group was one of over a million email messages posted annually to groups on one server alone. As this quote demonstrates, online discussion in these support groups have the potential to impact not only the degree to which patients and their family members feel emotionally supported by similar others, but also their treatment decisions. Despite the magni-

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tude of this revolutionary use of communication media, research on health online discussion from a communication perspective is limited. Therefore, the complicated ways in which communication is enacted in health online discussions are largely unknown. This gap in the literature is surprising in view of over two decades of research on computer-mediated communication.

With the rapid diffusion of computer-mediated communication in the 1990s, researchers often expressed concerns about the impact of this technology on communication. Specifically, they viewed this communication as inherently impersonal and hostile in nature due to lack of nonverbal cues (Walther, Anderson, & Park, 1994). Conversely, according to social information processing perspective (Walther, 1992; 1996; Walther, et al., 1994; Walther & Burgoon, 1992), people experience the same uncertainty and affinity needs regardless of the communication medium they utilize, and adapt their communication to meet these needs in accordance with the communication medium they are using. Therefore, computer-mediated communication is unlikely to exert uniform effects. Instead, it is important to examine the social context, including the content of communication, the communicators, and the nature of social relations between communicators (Shedletsky & Aitken, 2004; Spears & Lea, 1994; Walther, 1996).

Whereas researchers of online discussion in areas such as education (e.g., Aitken & Shedletsky, 2002; Hara, Bonk & Angeli, 2000) are increasingly heeding the call to examine the circumstances that influence this communication (Walther, 1996), the characteristics of health online discussions are largely unknown. Previous research focused on perspectives and needs of these groups’ participants (Wright, 1999; 2000; 2002), or on the content of communication (Ginnossar, 2008; Klemm, Reppert, & Visich, 1998; Klemm, Hurst, Dearholt, & Trone, 1999; Sharf, 1997). However, these studies did not examine

the dynamics in these discussions. In particular, it is unknown how factors such as the different categories of content identified (e.g., information and emotional support) influence the discussion. For example, are there types of messages that elicit more responses than others? What are the differences in responses to different messages?

Therefore, this chapter examines the dynamics of online discussion in a Lung cancer Internet support group. The need for this examination is supported by the potential of this new peer-to-peer media to change the nature of health communication through online discussion. It is also consistent with the call to examine specific contexts and circumstances of online communication, rather than assume uniformity of technological effects on communication (Walther, 1996). In addition, this analysis will enhance the knowledge of the communicative needs of lung cancer patients and their family members who participate in online groups, needs that are currently underexplored. Understanding these needs and their manifestation in online discussions’ dynamics will allow lay persons to cope better with having cancer, and to health care providers and health information professionals to help them in coping.

LITERATURE REVIEW

Face-to-Face (FTF) Support Groups

Support groups are an important mean by which Americans change their health behaviors. The leading reason for participation in such groups is having an illness. Although the distribution of groups according to diagnosis is unknown, cancer patients exhibit the highest overall tendency to participate in support groups (Davison, Pennebaker & Dickerson, 2000). The stories shared in support groups are considered to carry the weight of shared experience, the emotional potency of common suffering, and to provide an avenue for

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