

Chapter 20

Online Social Support Groups / Communities: Implications of Theoretical and Empirical Findings for Individuals Coping With Health Concerns

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ABSTRACT

Numerous studies over the past two decades suggest that people with a variety of health concerns are increasingly turning to online networks for social support. This has led to the rise of online support groups/communities for people facing health concerns. Researchers have found that these groups/communities provide patients, disease survivors, and caregivers a number of advantages and disadvantages in terms of mobilizing social support for their health-related concerns. This chapter will examine these issues in greater detail as well as the theoretical and practical implications of this body of research for patients who use online support communities to help cope with and manage a variety of health issues. It will provide an overview of online social support and health outcomes, discuss key processes and theoretical explanations for the efficacy of online support communities for people facing health concerns, and the limitations of this body of research as well as an agenda for future communication research on health-related online support groups/communities.

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INTRODUCTION

Numerous studies over the past two decades suggest that people with a variety of health concerns are increasingly turning to online networks for social support. This has led to the rise of online support groups/communities for people facing health concerns, growing from several thousand support groups/communities in the late 1990's to hundreds of thousands of groups/communities by 2012 (Chou, Hunt, Beckjord, Moser, & Hesse, 2009; Fox, 2011; National Cancer Institute, 2013; Wright & Bell, 2003). A survey conducted by the National Cancer Institute (2012) indicated that almost 5% of all adult American Internet users—approximately 7.5 million people—visited a health-related online support community during 2012. Another study found that 18% of people had used the Internet in the last year to find information from a peer with similar health concerns (Fox & Duggan, 2013).

Researchers have found that these groups/communities provide patients, disease survivors, and caregivers a number of advantages (and some disadvantages) in terms of mobilizing social support for their health-related concerns. Online health-related support groups/communities are frequently used by individuals with rare health conditions/issues that are not well understood by physicians, conditions/issues that are difficult for health care providers to explain in layperson terms, or if members of one's primary social network (i.e. friends and family members) have limited knowledge of a person's health condition (Campbell-Grossman et al., 2009; Tanis, 2008; Tong et al., 2013). Due to these issues, many individuals report that they receive inadequate informational support from their traditional social networks and health care providers; and they appear to perceive online support groups/communities as a better alternative for receiving health information (Wicks et al., 2010).

Moreover, research in this area has found that online community members enjoy the ability to draw upon the collective experience of other online participants who are dealing with a similar health issue in ways that are not possible in the face-to-face world. For example, the Internet allows people to access and interact with others in health-related online communities that cross geographical and temporal boundaries (Rains & Wright, 2016). In addition, other participants within these online communities appear to replace or extend traditional offline support networks in terms of providing greater access to different forms of social support. Accessing support providers online has the added benefit of finding people who are available in a larger, easier to maintain, network of (often) geographically separated individuals compared to face-to-face sources of social support (Ellison et al., 2007; Kim & Lee, 2011; Walther & Boyd, 2002). Online support groups/communities can also help individuals facing health concerns during times of stress and transition to access new networks of support, such as providing connections to others facing the same or similar transitions and stressors (such as if a person moves to a small town where the likelihood of meeting others living with a similar health condition is low).

In addition to convenience, online sources of social support can help individuals with health problems overcome accessibility barriers and high service fees associated with other (more traditional) sources of information and support, such as therapy (Barrera, 2000). The asynchronous and mediated nature of online communication helps alleviate time and space barriers that exist for support settings that require the simultaneous presence of conversational partners (Turner, Grube, & Meyers, 2001). Online support groups/communities often offer people who are coping with health problems higher quality health information and support for health behavior change than is available among traditional, face-to-face sources of support (Wright & Miller, 2010).

This chapter will examine each of these issues in greater detail as well as the theoretical and practical implications of this body of research for patients who use online support communities to help cope with

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